All Ireland Traveller Health Study

Our Geels

Technical Report 3

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Qualitative Studies

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Qualitative Studies
Part A of Technical Report 3

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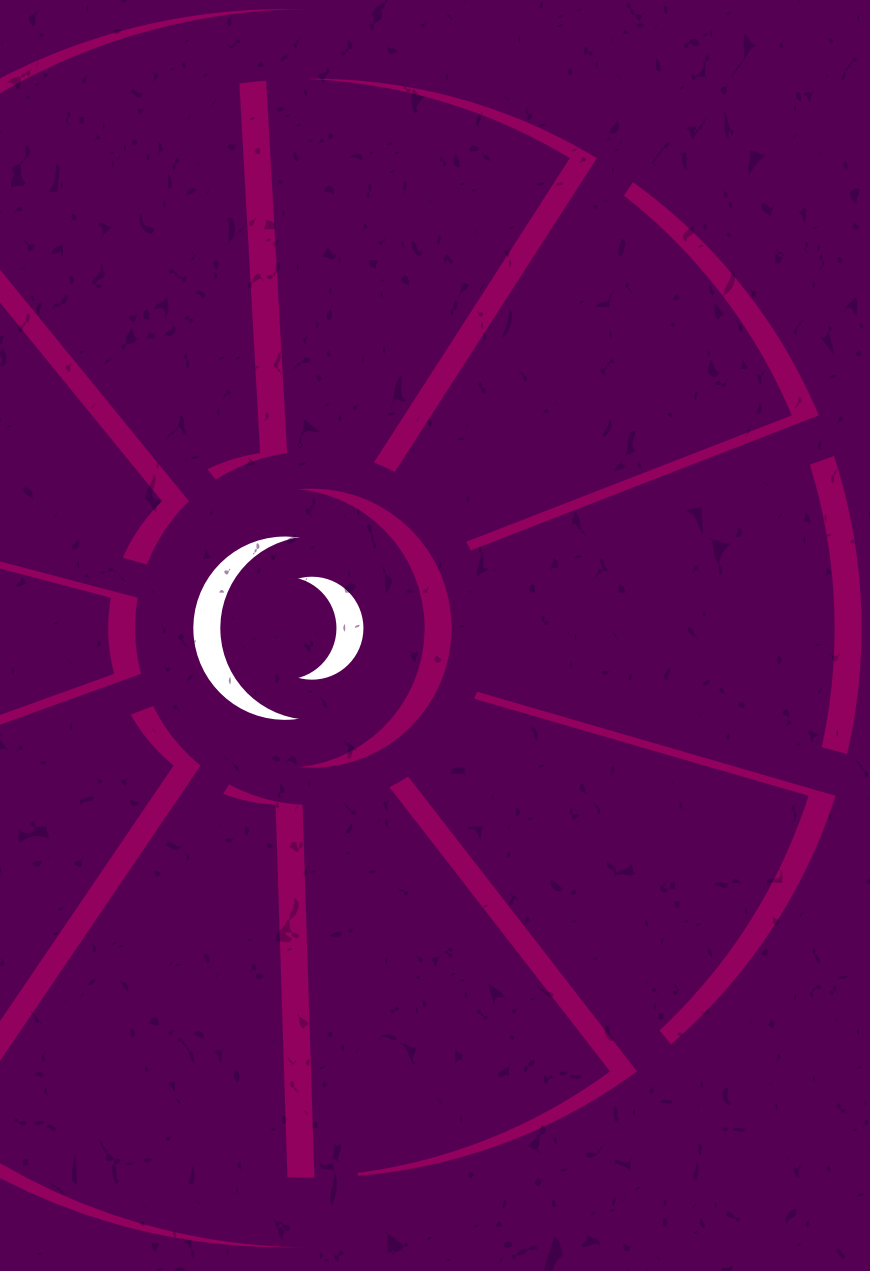
Introduction



Introduction

The All Ireland Traveller Health Study (AITHS) comprises 3 Technical Reports covering the various data collection phases of the project. Here in Technical Report 3 we focus on the qualitative consultation process undertaken with Travellers themselves and with relevant service providers (section A), and a quantitative survey of Service Providers (section B). Finally, in section C, we discuss the overall findings of the study as a whole with recommendations.

In Technical Report 1, we address the background to the AITHS and review as part of this the context for the study as a whole, which addresses the history of Traveller health policy over the last four decades, the importance of the wider health determinants influencing Traveller health and various exemplars of good practice for promoting Traveller health generally and providing appropriate healthcare. We refer the reader to this section for further detail and information on the background that informs the rationale for the census and vital statistics studies reported on in Technical Reports 1 and 2 and the need for a consultative process, described in the present Technical Report 3.

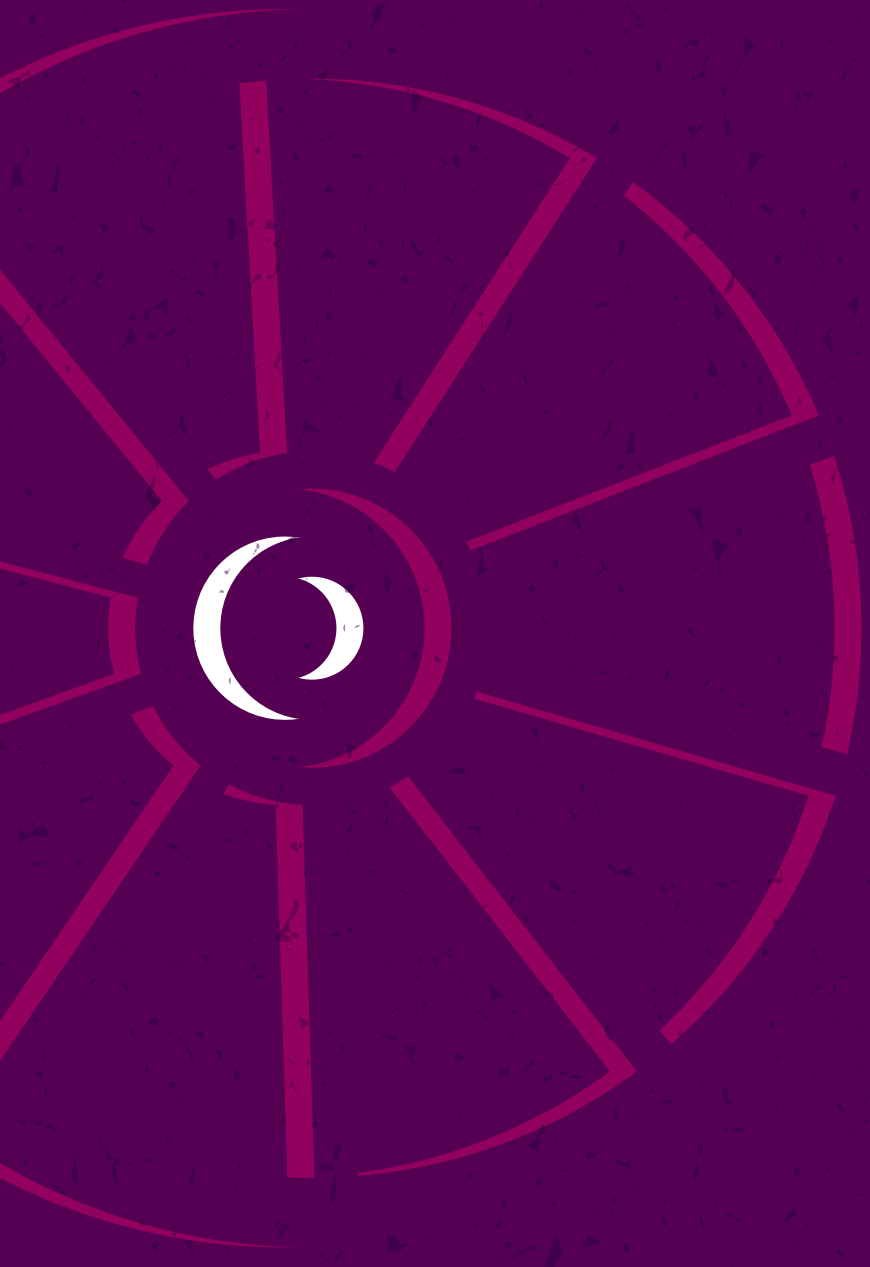
The present report therefore needs to be interpreted in the context of the other parts of the study. In seeking to understand how Travellers perceive their own health, the factors determining their health and the impact on their health of engagement with Service Providers, particularly in the health sector, we are situating this exploration as part of the wider project. We have already reported in the census survey the social circumstances of Travellers and the prevalence of various factors known to determine health, including living conditions, personal lifestyle and health status. In that section too we have presented frequency of engagement with the healthcare system and various factors well established as possibly influential on utilisation patterns.

In the vital statistics reports in Technical Report 2, we have examined mortality patterns in the Traveller community and causes of mortality. We also examine patterns of fertility and we profile the birth cohort established especially as part of AITHS. That report too considers specifically the health status of Prisoners and what information is available on their health status.

Technical Report 3 therefore presents an opportunity to capture the voices of Travellers themselves and of Service Providers to triangulate more fully the quality of the Traveller experience and complement the information collected in other parts of the study as a whole. We describe the process more fully in the methodology but the planning and follow through of this part of the study is grounded in the preparatory work undertaken elsewhere in this report.

Technical Report 3a is qualitative in its approach. The purpose is to listen and understand what the issues of relevance to the lives of Travellers are in their own estimation and to hear how these issues have a bearing on their health, as they themselves see it. This information is crucial to translating the findings of all sections of AITHS into evidence-based action and goes to the heart of motivation and engagement of both Travellers and Service Providers. This is also a rich opportunity to explore with Service Providers their perceptions of the issues and to link this to the view of Travellers in order to explore commonalities and possible future solutions.

Methodology



Methodology

The qualitative component of the AITHS aimed to ascertain the perceptions and experiences of members of the Traveller community, Traveller advocates and Service Providers (via multiple qualitative research methodologies) in relation to Traveller health (including the broader social determinants) and services relevant to their health.

Overall Design[1]

The study team began looking at a range of appropriate data-gathering techniques while factoring in the goals, purpose and scope of the research. This aspect of the project advocated a strongly contextual and holistic approach at all stages, from needs assessment through to service delivery. A broad draft framework for the qualitative component was developed in order to enable consultation with the Regional and National Traveller Health Networks (NTHNs), the Health Service Executive (HSE), the Technical Steering Group (TSG), and Northern Ireland (NI) Stakeholder Group and other relevant parties. After a rigorous consultation process and careful consideration the study team distilled the methodological approach to include generic focus groups; topic-specific focus groups; semi-structured interviews with Traveller Advocates and Service Providers; Traveller case studies and young people's participatory research.

This aimed to achieve a consistency between best-practice grounded-theory principles while also accounting for the scope, complexity and diversity of the issues associated with health status and health services utilisation of Travellers (Glaser and Strauss, 1967). The Traveller health projects/ equivalent groups proved crucial to the research process and fieldwork. Pavee Point in particular provided advice and facilitated access to participants; in addition to practical help such as offering venues for meetings and help with training. This allowed for a deep knowledge of the researched community and fostered ongoing relationships and trust building. Both the training and capacity building of Traveller peer researchers and their feedback remained important considerations. The planning for the fieldwork and the capacity-building aspect proved to be a major achievement of the study in terms of how research can have a positive effect on community development of the researched group.

Theoretical Basis for the Traveller Qualitative Study

This study is aimed at providing an understanding of health status, health behaviour, health beliefs and health service provision among members of the Traveller community. Our commitment to train and work with Peer Researchers also underpins the research approach. As a methodological approach, qualitative research aims to provide an emic[2] understanding of the life world of those studied. That is, it seeks to discover locally understood social realities and to draw attention to processes, meanings and structural features. The approach is reliant on 'thick description' and context (Geertz, 1973). It

[1] Southern Ireland (ROI) and Northern Ireland (NI) refers to the politically defined rather than geographically defined parts of Ireland.

[2] The emic perspective focuses on the intrinsic cultural distinctions that are meaningful to the members of a given society (see Headland et al., 1990).

also provides a platform for a hard-to-reach community where the data 'speaks for itself' in the form of narrative and vignettes. It is interested in nuanced aspects of social behaviour and beliefs and is therefore drawn to looking at maximum variations and outliers in addition to observed associations and patterns. It also looks at the sequence of events as these unfold and is interested in dynamics. The design was intended to complement the quantitative approaches already undertaken in order to generate a more three-dimensional picture of Traveller health issues. The combination of methods also meant that we have been able to triangulate between the various methodological approaches to confirm and/or refute information already obtained and to consider issues not previously discussed (Flick, 2006; Kvale, 2009).

Ethical Approval

Approval for the whole study was applied for in ROI through a University College Dublin Ethics Committee and was granted in November 2007. Amendments to the study were subsequently applied for via the same committee as the study rolled out in response to the research requirements.

Approval in NI was applied for and granted in two parts. Initially approval was granted for the Census and Vital Statistics in December 2008. Approval for the Consultative Studies was granted in December 2009. The latter involved the qualitative component as outlined, and the Health Service Provider Study.

The application for approval in NI required separate approval from the Office for Research Ethics Committees Northern Ireland (ORECNI) and from the 5 Health and Social Care Trusts. The application and approval system changed during this study period in an attempt to make the application procedure more rational. The process proved to be extremely time-consuming and taxing despite the good will and assistance of the individuals involved.

Focus Groups

The aim of the focus groups was to include Travellers' voices, views, individual experiences and to give insight while also identifying models of good practice (Barbour, 2008). Twenty-four focus groups were conducted (20 in ROI and 4 in NI, see Table 3A. 1 and Table 3A. 2). Two further focus groups were planned towards the end of fieldwork in ROI but although arranged these were cancelled at the last minute as the participants were unable to attend.

All of the focus groups were audiotaped and all except two were transcribed verbatim with the confidentiality and anonymity of respondents guaranteed[3]. Each focus group was facilitated by a UCD researcher and a trained Traveller Peer Researcher. Each group lasted for a maximum of one-and-a-half hours. Respondent burden was considered, however given the interaction with and between Travellers, it was felt appropriate that these sessions last longer than conventional focus groups. Traveller peer researchers not only increased the research capacity within the Traveller population but also increased the degree of sensitivity of the research study. The detailed planning, preparation and consultation helped refine the research focus and enabled the process.

[3] Two were inaudible to the transcriber because of background noise and regrettably could not be used.

Topic Areas

The study team developed an extended list of potential topic areas for the focus groups. These were informed by the cumulative experience of the study team in the field of health studies, a detailed consultation with Travellers and other stakeholder groups throughout the development of the census and quantitative studies, as well as previous scoping and information accrued from broad literature searches. This included research into topics that, following consultation, were purposely omitted from the census, as it was decided that some topics were considered inappropriate to include in a survey with the Traveller community and should be left to be explored using qualitative data gathering techniques (for example, drugs, sexuality, or women and violence). As part of the iterative process the emerging Census data, the initial findings from the focus groups and further consultation were factors in the final determination of topics. The research and analysis was based upon formative principles, that is, the final instruments reflected the process of consultation, and were not fully predetermined.

Through further consultation with Traveller projects/equivalent groups in both ROI (via the NTHN and the National Traveller Reference Group) and NI (via the NI Stakeholder Group) this extended list of potential topic areas was distilled down and the topics listed in Tables 3A 1 and 2 emerged as major points of concern. One focus group was designed to be 'floating' without any topic assigned. This allowed scope for further data to be collected if necessary. However, the team was confident that saturation had been reached.

Table 3A. 1: Focus Groups (ROI)

Focus Groups (ROI)	Number of focus groups	Tape/Notes
Women's Health	2	Tape
Men's Health	2	Tape
Older Women's Health	1	Tape
Young People	2	Tape
GP's, A & E, Medial Card and Dentists	2	Tape
Mental Health and Suicide	2	Tape
Addiction	2	Tape
Education	2	Tape
Work	1	Tape
Accommodation	2	Tape
Caring in the Community	1	Tape
Parental Perceptions of Child Health Services	1	Tape
Institutions	2 Cancelled	

Table 3A. 2: Focus Groups (NI)

Focus Groups (NI)	Number of focus groups	Tape/Notes
Accommodation	1	Tape
Mental Health and Suicide	1	Tape
Access to GP and Services	1	Tape
Generic	1	Tape

The focus groups were either more open in style (generic) or specific around a particular topic area. The generic style is open and designed to allow the usual and unusual aspects of Travellers' experiences to emerge. Travellers could discuss at their own pace, talk about and prioritise issues they perceived as being important. Due consideration was given to data already gathered from the census and from other sources as we developed queries/questions/themes iteratively. Further scoping was done with relevant Traveller Networks/advocates with particular expertise in specific areas of Traveller health to inform the topic guides for focus groups. Both the generic and specific approaches were piloted. In practice, many of the same issues of concern arose and crosscut each focus group and topic area. This further validated the data.

Recruitment

The focus group strategy included a purposeful sample specifically to look at maximum variation. At the planning stage the study team anticipated that there might be significant variation between health status, experiences, utilisation by gender, age and differences in geographical location to warrant focus groups and to include all of these variants.

Early feedback during the consultation process suggested that it would be more culturally appropriate, to facilitate some gender-specific focus groups. Therefore there were focus groups on men's health, women's health, older women and gender-specific focus groups on addiction. Also, if a focus group involved people in a pre-existing group, (for example, people with specific knowledge of an area of Traveller health) then it was rational for this group to be a mixed gender group.

Participation was on a voluntary basis with a minimum of 5 and a maximum of 12. While Traveller Peer Researchers from the census and quantitative studies were among those recruited, other members of the community were afforded the opportunity to participate. This made it more inclusive and allowed a variety of different voices to be heard.

Training of Peer Researchers and Piloting

The inclusion of Peer Researchers was central to the research approach and was vital in order to conduct the research successfully. The criteria for Peer Researchers required that they should be Travellers who:

- have a relationship of trust with other Travellers in the community
- are willing and available to take part in basic training (qualitative research methods) and to support focus groups if required
- have the potential to build on the training in order to increase the Traveller community's capacity to conduct research in the future beyond the 'Our Geels' project

The training was piloted in advance in ROI. Peer researchers were trained using ethically approved protocols designed and piloted by the study team. Peer researchers from several of the projects in the Eastern Regional Traveller Health Network (ERTHN) region attended the pilot training session facilitated by UCD. Following a review and lessons learned from the first training session Traveller groups became more directly involved in delivering the training. Therefore, a second revised training session was facilitated by Pavee Point in conjunction with the ERTHN, closely supported by the study team. Two pilot focus groups were conducted. At each of the pilot focus groups and all of the subsequent focus groups a peer researcher co-facilitated with a member of the UCD research team. The first open pilot was 'Women's Health' and the second 'GP/A&E/Medical Card/Dentists'. Feedback from participants, peer researchers and stakeholders was given careful consideration. An initial review of the process was made and led to a number of (mostly minor) considerations and changes to the protocols.

The quality of the data gathered in the pilot focus groups was deemed of such a high value that data from both focus groups has been included in the data set. Both topic-specific and generic approaches appeared to work in a complementary fashion.

Fieldwork

Early in the consultation process, the study team invited members of the NITHN to offer feedback on whether or not they would be able to support the qualitative study. This information was central to the planning of the study. It was decided to move forward on a regional basis rather than a Traveller project basis.

Consequently, the island was divided into 1 qualitative area for NI and into 5 areas in ROI. A qualitative coordinator was appointed by the NITHN to work with the assisting projects/groups in each area and liaise with the study team.

Northern Ireland

The qualitative research started later in NI (this was due to the requirements and timing of the OREC ethical approval process). The study team worked in close consultation with stakeholder groups such as An Munia Tober, the DHSSPSNI and key individuals in NI in order to design this strategy. This consultation included outlining the qualitative approach used and issues that had arisen in light of Traveller and stakeholder experience in ROI.

The focus groups took place in 2 of the 5 Health and Social Care Trusts in NI reported to have the highest density of Traveller families while also reflecting the urban/rural balance. Training of Peer Researchers, in conjunction with Pavee Point, was facilitated by a designated fieldwork coordinator for NI who worked in conjunction with the NITH Network to make it possible.

Method of Analysis

Data analysis was iterative running concurrently with the data-gathering process. Feedback from Travellers, peer researchers and stakeholders was included in the analysis. The validation stages for the focus groups also included using the constant comparison method of crosschecking the data from each focus group with other focus groups for overlap and disjunctures.

A manual thematic analysis was conducted by 3 members of the study team who independently analysed the data before coming together to discuss their findings. In addition, 4 inter-raters[4] individually read sections of data from a range of focus groups for key emerging themes and met with the qualitative team to compare and contrast findings. A high correspondence of themes emerged from all 4 inter-raters, which further validated the process. Findings were also triangulated with other study data.

A literature review was undertaken and is incorporated into the bibliography.

Case Studies

The qualitative team designed case study protocols. Following discussions between members of the research team, Pavee Point and the NITHN a template was agreed whereby Travellers themselves would produce a number of case studies. This template ensured a uniform approach to data gathering. Pavee Point and the NITHN facilitated the recruitment and data-collection process. Five case studies were selected by the NITHN. These were subjected to thematic analysis by the UCD research team and data from these was incorporated into the broad data set. This afforded the opportunity to gain information from difficult-to-access areas or groups of Travellers not appropriately captured via focus groups or interviews.

Semi-structured Interviews

Twenty-seven semi-structured interviews were conducted in ROI and in NI with key discussants as listed in Table 3A. 3. These interviews served to complement, or in some cases (when a focus group was not appropriate) supplemented the focus groups and added a further dimension to the research.

The study team compiled an extended list of potential interviewees. These candidates were determined after full scoping had been carried out with the relevant agencies and personnel and with full approval

[4] Inter-raters are individuals who interpret qualitative data independently of each other. This is to ensure reliability of the data interpretations. This is a recognised validating process in qualitative research.

of the respective stakeholder groups. The findings of the focus groups also influenced who the key discussants were as we sought to investigate various themes that had arisen during the data collection. The list was broken down as follows:

- Professionals who have specialist knowledge in terms of policy.
- Professionals or individuals who are at the operational level in terms of policy implementation.
- Persons with special knowledge who interface on a daily/regular basis with Travellers and can comment on implementation of policy at the local level.

Table 3A. 3: Semi-structured Interviews

SSI #	Interviewee	Tape/Notes
SSI01	Consultant 1	Tape
SSI02	Consultant 2	Notes
SSI03	Consultant 3	Notes
SSI04	Consultant 4	Notes
SSI05	Consultant 5	Notes
SSI06	Consultant 6	Notes
SSI07	Consultant 7	Notes
SSI08	Service Provider 1	Tape
SSI09	Service Provider 2	Tape
SSI11	Service Provider 3	Tape
SSI12	Service Provider 4	Tape
SSI20	Service Provider 5	Tape
SSI21	Service Provider 6	Notes
SSI22	Service Provider 7	Tape
SSI13	Traveller Advocate 1	Tape
SSI14	Traveller Advocate 2	Tape
SSI15	Traveller Advocate 3	Notes
SSI16	Traveller Advocate 4	Tape
SSI17	Institutions 1	Tape
SSI18	Institutions 2	Tape
SSI19	Institutions 3	Notes
SSI23	Child Services 1	Tape
SSI24	Child Services 2	Notes
SSI25	Other 1	Tape
SSI10	Other 2	Tape
SSI26	Other 3	Tape
SSI27	Other 4	Tape

Fieldwork

The interviews followed detailed developed and approved protocols. This involved letters of invitation, participant information sheets and consent sheets that were sent out prior to interview. The interviews took place at a venue agreed by the parties concerned, lasted up to one hour and were conducted by researchers from the study team. The interviews were audio-recorded except when the interviewee said that they did not wish to be recorded in which case notes were taken and written up immediately afterwards. For each semi-structured interview, an aide memoire was developed that included basic questions to be covered. However, these were adapted to the specific interview needs in question. The process was iterative as themes arose from the analysis in process. Several interviews with consultants and GPs were conducted via telephone as a pragmatic alternative to access via face-to-face interviews.

A template was developed which included questions on service provision and Traveller utilisation, and probed respondents about their experience of offering their service in relation to barriers and opportunities and any examples of good practice. This was used for all the interviews with consultants for a consistent approach. However, it allowed flexibility and to some extent was iterative as we added areas for question reflexively as we gained more data.

Analysis

Audiotapes of the semi-structured interviews were transcribed as per Table 3A. 3. Data from each interview was analysed by individual interviewers and the main points extracted and discussed within the team. These were subsequently integrated thematically into the overall qualitative data set.

When the interview involved the telephone, notes were taken during and immediately after the interviews, typed up and circulated to the research team on the same day and similarly analysed and integrated into the data.

The team was confident that saturation had been reached during the collection of the semi-structured interviews. In order to preserve anonymity of these 27 respondents their contributions are not numbered in the report though the quotations cited can be mapped to their archived transcript.

Young People's Participatory Research

The aim of the young people's research was to gain an understanding of young Travellers' experiences in relation to health. It aimed to explore their definitions of wellbeing and daily experience as health determinants.

The methodology was co-designed with the study team and the Traveller youth team based in Pavee Point following the ethos of being 'for, by and with Travellers'. Working with the youth team, (which included members from the Traveller community) fostered continuity and trust. The approach involved young people from the outset and privileged young people's voices on an equal basis with adults (Turner et al., 2006). It explored what young people understood about being a young Traveller in terms of their wellbeing.

The research was conducted at two research sites in ROI, one urban and one rural. This allowed for some comparability between areas. Young people from both genders from the age of 10 years were invited to participate. Following approved and detailed protocols regarding recruitment, invitation, participant and parent information and consent and with due regard to the appropriate checks relating to working with young people, the parents of the young people gave their consent for their child to attend the activity sessions and assent was given by each child attending the sessions.

After consultation with the youth team a range of alternative research methods were deployed. These included painting, drawing photography and drama/roleplay. Participatory methods were used to explore health topics and were incorporated into the design. In the event, painting, games and roleplay via devised performance were chosen. The results will be fed back to the young participants in each area through the Traveller organisations and youth leaders as part of good practice.

Urban Context

In the urban sessions the young people contributed to the study via photo chat, role-play and devised performances and complementary artwork. One UCD team member and 2 members of the youth team were present as activities were developed into creative outputs. These were discussed with the young people as they interpreted their work/data.

Three UCD team members attended the final presentation by the young people to an invited audience of Travellers and Traveller representatives. Further discussion and feedback took place between the audience and the young people.

Rural Context

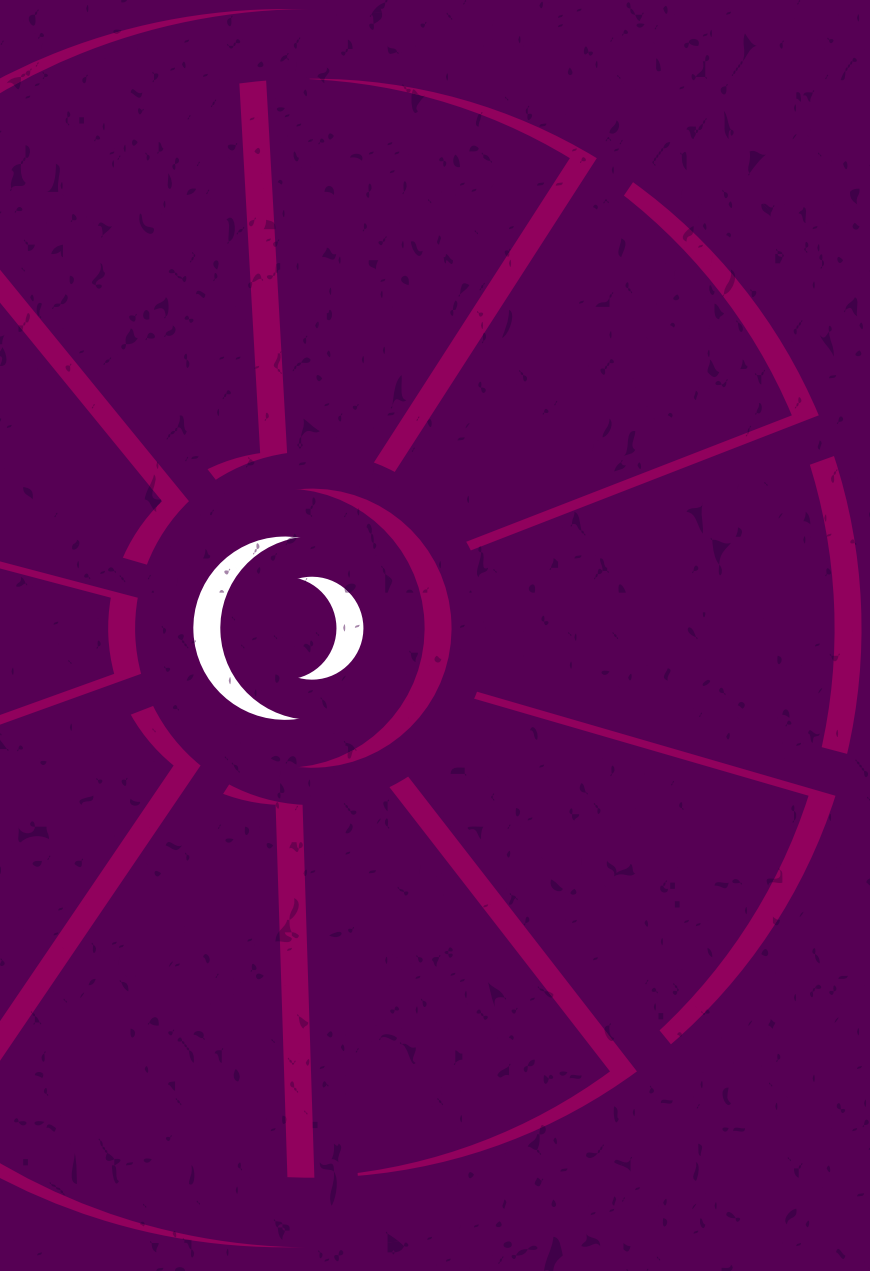
The rural sessions were based upon the same principles when the research followed a similar trajectory when games, photo chat, drama roleplay and art were the preferred methods of participation. The timeframe for this was shorter than the urban research and there was no presentation to an audience beyond the UCD/Youth team facilitating the participation in this case.

Analysis

Data, via notes, flip charts, Post-it notes, paintings and other activities, such as scenarios and individual and group presentations were collected during and at the end of each daily session. De-briefing with youth teams occurred on both occasions at the end of each day and at the end of the week (urban context) or weekend (rural context)

In addition, a member of the UCD team met with the youth leader from Pavee Point on several occasions before, during and after the research to corroborate events, outcomes and themes arising. This data was included into the relevant sections of the report thus giving young people a voice in the overall report rather than being contained in one separate section.

FINDINGS AND DATA ANALYSIS



As a general observation, this is a presentation of views of respondents, not an audit of services as delivered and should be interpreted in that spirit. Other quantitative sections of the report reflect rates of utilisation, for instance. The data reflects the perceptions of Travellers, advocates and a range of Service Providers based upon their understandings and experiences. We present the data thematically based on what emerged from the analysis itself. However we have sequenced it to reflect the broader health determinants model that underpinned the AITHS as a whole. Accordingly we explore first the issues affecting Travellers in the 21st century, covering living and working conditions and aspects of lifestyle, before focusing on health practices and interface with the healthcare system.

Travellers and Change in the 21st Century

Background

Modernisation and the move toward city-centric industrial life in the west have arguably influenced Traveller culture, lifestyle and health in significant ways[5]. Travellers (symbolically and literally) have lived on the margins of mainstream society. The move toward modernity has increased the social, political and economic impoverishment and isolation of Travellers on an unprecedented scale[6]. As western societies developed and industrialised (and organised around the principle of national and civic identity) these changes were to have a profound effect on Travellers in Britain, Ireland and abroad since their lifestyle and cultural survival hinged on traditions of social and economic exchange and skills that had allowed them to be independent and peripatetic.

'*…I think there is confusion around identity and confusion around trying to fit into the local community …Like there's a lot of reasons why they might not want to like, discrimination, racism, stigmatisation, there's a lot of issues that affects Travellers on a daily basis you know and the whole thing of identity crisis. Travellers have and are going through a major identity crisis at the moment*' (Men 1).

The first undisputed record of Gypsy Travellers in Britain goes back to 1505 (Fraser, 1992). Travellers until relatively recently have received little sociological and anthropological attention. We reviewed relevant policy and literature on Travellers in the Republic of Ireland in the background section of Technical Report 1. Recent focus on Travellers in Britain has come from a variety of disciplines. Significant works include Okely (1983), Feder (1989), Van Cleemput and Parry (2001), Smart et al. (2003), Treise and Shepperd (2006), Parry et al. (2007) and Van Cleemput et al. (2007). Of particular note are two key reports on the health of Travellers in England. The South West Public Health Observatory conducted

[5] Laslett's (1979) groundbreaking work mapping English society before the industrial revolution through to the 20th century offers an historical glimpse into the social structure of a modernising western society undergoing major transformation and it documents the effects of change. No account of how such change has marginalised Travelling people has to our knowledge been documented in similar detail.

[6] For some discussion and useful highlights of major developments surrounding 'modernity' (and late modernity or postmodernity since the 1970s), see Lasch (1985), Lash and Freidman (1992), Lash and Urry (1987).

a literature review of a number of small-scale research studies in 2002 and the Department of Health commissioned research by Sheffield University in 2004. These focused principally on the health status of Gypsies and Travellers and a number of comparator communities (see Communities and Local Government Report, 2009). In addition Hawes (1997) provides important commentary on Travellers in relation to health services. This draws upon earlier significant work discussing the typology between cultural and social understandings and prevailing health problems among Travellers (Hennink et al., 1993).

Irish Travellers

Within the Irish context historical and literary reference at once romanticises and demonises Travellers. For example, Irish Travellers were popularised through the Celtic literary revival as the nascent Irish state developed. In this context Travellers came to represent, 'the embodiment of freedom, wildness and danger' (Fanning, 2009) in much the same way 'the Irish' had been depicted in earlier historical reference (see Foster, 1993; Bourke et al., 2002).

Travellers are often depicted in a one-dimensional and negative manner in a process classically referred to as a 'moral panic', that is in terms of a threat to the social order (see Cohen, 1973). These anxieties, often fanned by media representations have helped create perceptions of Travellers as 'folk devils' (see Cohen, 1973; Helleiner, 1998a, 1998b). Research on Irish Travellers while historically scant[7] , is growing[8] and on the health of Travellers in Ireland is now disparate but expanding[9].

Recognition in Law of Ethnicity and Traveller Culture

A central issue in discussions surrounding Irish Travellers is that of identity and ethnicity. The right of claim as a distinct ethnic group has been contentious but was conceded in Britain[10] (see van Cleemput, 2000). In Britain and NI, Irish Travellers are afforded the distinction and legal protection of a minority ethnic identity[11] .

'In the last decade of the 20th century, a number of significant steps were taken that, for the first time, formally placed Travellers right at the centre in the struggle to tackle racial prejudice and discrimination in Northern Ireland. The Race Relations (NI) Order 1997 and the Northern Ireland (1998) Act give formal recognition to Travellers as a distinct ethnic group' (Ginnety et al., 2006:4).

Noonan estimated that between 30-40% of Travellers in NI live in Belfast (Hainsworth, 1998:154). Travellers in NI are defined as, *'an indigenous minority ethnic group with a shared history who have been living in Northern Ireland, as well as the Republic, for centuries'* (Ginnety, et al., 2006: 3).

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7 Fanning (2009) presents a useful critique of the historical literature.

8 See for example, McCarthy (1972), Gmelch (1975), Gmelch and Gmelch (1976), Joyce (1985), McCann et al. (1994), McLaughlin (1996), Helleiner (2000), Bhreatnach (2006), Lanter (2008) and Kirk and O'Baoill (2002).

9 See for example, Ginnety (1993), Taskforce on Travellers (1995), Barry et al. (1989), Greenan (2009), Duggan-Jackson (2000), Hodgins et al. (2006), and Ginnety et al. (2006).

10 In Britain for example The Caravan Sites Act (1969) did not consider Travellers in terms of culture and ethnicity until the Commission for Racial Equality determined that Gypsies formed a distinct ethnic group.

11 The Race Relations (NI) Order (1997) and the NI (1998) Act give formal recognition to Travellers as a distinct ethnic group.

Noonan provides discussion on a range of explanations on Traveller identity and Traveller origin and a detailed history of legislation in NI in respect to Travellers (cited in Hainsworth, 1998).

Travellers in ROI are not defined as an ethnic group and this is the source of political tensions (between the ROI Government and European Government positions), and academic tensions (defining baseline and locating research within an agreed body or cannon of literature). Definition is important in exposing multiple and interconnected factors influencing health gain. A number of key reports in ROI have pointed up associated factors such as poor educational achievement, very low employment rates and poor health status, as discussed in Technical Report 1. In NI too more recent evidence has emerged (see Gordon et al., 1991; DPH Report (EHSSB), 1989; Paris et al., 1995a; Irwin and Dunn, 1996; Hainsworth, 1998; Western HAZ (NI), 2003).

The qualitative data indicated that the concept of Traveller ethnicity remains a central issue to Irish Travellers in ROI and NI and one that they believe has consequences for them not only in terms of cultural survival but also in terms of health and life chances. They also recognise that definitions of Traveller identity have important policy implications (see also Coates et al., 2008).

Identity and ethnicity strongly emerged as a central theme of concern throughout all the various qualitative data sources that hang like a pall over many aspects of Traveller life. Traveller identity therefore needs to be addressed head-on because of the perceived distinction between Travellers and the settled community, and the relationships between them are significant, socially, politically and economically.

'Traveller ethnicity is a key factor that has to be taken into account in identifying and responding to the needs of the Traveller community. Culture and identity shape the needs of a group. Policies and programmes that respond to needs will only be effective to the extent that they take into account the culture and identity of the group concerned' (Equality Authority, 2006:9).

The oral tradition of Irish Travellers has meant that Traveller genealogies and factual histories remain problematic, blurred and contested. The notion for example, that they were dispossessed settled people (although with no basis in fact) fitted with the Irish nationalist project, but is interpreted by Travellers as disenfranchising them of their cultural heritage, that is, the right to travel (Pavee Point Publications, 1992). Irish Travellers perceive themselves as essentially different from Gypsies.

Recent history is illustrative of how mainstream attitudes and legislation shaped Travellers' experiences in a modernising Ireland. For example, in 1960 the Commission on Itinerancy sought to integrate and assimilate Travellers into the general Irish community and thereby reduce to a minimum the disadvantages to themselves and to the community resulting from their itinerant habits (Fanning, 2009).

The problem arises because (despite the increasing numbers of Travellers living in houses as identified in the census data earlier) many remain by choice and aspiration nomadic and their lifestyle and culture hinge around travelling. This is an important distinction as our data confirmed that nomadism has both existential/mental health and material/physical health consequences. Travellers are, and have been a distinct group in Irish society over many centuries, separate from vagrants. The hallmarks of their culture have been family-centred independence and self-reliance with a strong duty of care for kin (Clear, 2007). This made the Elizabethan notion of 'the sturdy beggar' much harder to apply to Travellers even though many had been driven to begging and hawking in lean times to support families.

In Ireland (ROI and NI) significant work has sought to make a case for the ethnic status of Travellers (Gmelch and Gmelch, 1976)[12] (See also Equality Authority, 2006; McVeigh, 2007 and Fanning, 2009). The ethnic status of Travellers in the ROI remains nebulous, and attitudes to this are at best agnostic.

The received definition of 'Traveller' is one that interprets Travellers as an ethnic group, that is, separate and different from, but living alongside the settled population and sharing much of the same culture, but experiencing this differently[13]. Anderson's concept of the 'imagined community' is instructive here (Anderson, 2006)[14]. The qualitative data for example, illustrated that for Traveller men allegiance to national identity was subordinate to the Traveller community and Traveller culture.

'…I would say that I was born into the Traveller Community so I would consider myself first and foremost to be a Traveller' (Men2).

'…If there were two stones in the park, would you say you were a Traveller, or Irish before you were a Traveller? I put it to you this way - I feel more comfortable being around a Traveller than I do feel around an Irish settled person' (Men2).

'…You shouldn't be proud to be Irish because you should be proud to be a Traveller…. You shouldn't be proud to be Irish the way the Irish people have treated you and your family and your grandparents…and the way they discriminate and racism against ye you know' (Men2).

'…We're Travellers but we are Irish. That's something they can't take away from us…but if we are not recognised by our own' (Education 2).

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[12] It is perhaps worth noting that anthropologists have also pointed up the socially constructed nature for example of national identity. See Gellner (1983) and Eriksen (1993).

[13] See also Simmel (1908) Concept of 'The Stranger'.

[14] It is imagined because the members of even the smallest nation will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion. In fact, all communities larger than primordial villages of face-to-face contact (and perhaps even these) are imagined. Communities are to be distinguished, not by their falsity/genuineness, but by the style in which they are imagined (Anderson, 2006)

Travellers are sensitive to the celebration of other cultures and to what they perceive as discrimination by settled people and by modern formal structures.

'…Within the education criteria there is nothing about the Travelling community. All you learn about is different minority groups and celebration days within the schools…We are Irish Travellers who have been here for centuries and there is nothing about the Irish Travellers, and Travellers always say, oh I'm proud to be Irish' (Men2).

'…We have to integrate, but not assimilate. Now that's the difference there is that yes we want to integrate but not assimilate. Travellers are always going to be Travellers because discrimination plays a main on our daily lives, and I'm talking maybe once a week' (Accommodation1).

'…If they are going to teach the culture it is also going to break that stigma. That's between the settled and the Travellers. It'll let the people know that we are not alien' (Education 2).

The ideal of the nomadic lifestyle remains a central pillar in terms of Traveller identity. Some travel regularly, others periodically, others have an ideal of travelling rather than actual defining behaviour. Some had not travelled for a considerable time. But Irish Travellers who took part in the study agreed that they wanted to reserve the right to travel. In this sense Travellers ascribe to nomadism as a cultural 'state of mind' (Parekh, 2000). They frequently cited legislation such as the "trepass act" (Government of Ireland, 2004) as restricting travelling and they see this as discriminatory practice. Travellers believe that this has also compounded pre-existing social and health disadvantages of Traveller lifestyle.

'…There's all these fines and all…They are not allowed to travel….that's because of the anti-trespass laws 2001 – that prohibit the Travellers from travelling around the country. Because there are several cases where, their homes have been seized and brought to court and the kids have been removed to care' (Men1).

'…If you've got trespass legislation and you've got the Indigenous Clause, why are they calling Travellers 'Traveller' and why are they saying Traveller-specific accommodation' (Accommodation1).

The prospect of settling into permanent accommodation is interpreted as a direct attack on traditional Traveller culture and support structures. Travellers appeared to have a well-defined and clear understanding of their 'imagined community'[15].

Identity and Homogeneity

The data suggest that while Irish Travellers identify as an ethnic group, they are not homogeneous. Within the Traveller community different belief systems, culture and language are expressed and experienced. The data evidenced a heterogeneous community of individuals and families. Their needs, aspirations and orientations reflected a diversity that if officially recognised would require specific responses to meet their needs and counter and challenge the prevailing tendency of stereotyping.

[15] The Equality Authority Report (2006) considers important academic considerations of Traveller ethnicity including Barth's Ethnic Groups and Boundaries (1969) but omits Anderson's concept.

Traveller culture, as with all cultures, is diverse. The data showed broad and different experiences of the world while, for example, some Travellers are more isolated than others.

'…Even within the Travelling community, say the [X family] right, who rarely mix with others, even with other Travellers. They want to be in a site by themselves' (Men2).

Travellers also occupy different positions on the economic spectrum. Much of the literature documents Travellers in reduced circumstances, but others appear to be more financially comfortable and still others appear to be well off. Socio-economic status and deprivation may also be a feature of where Travellers are geographically located. Travellers may be financially disadvantaged, but in rural areas for example, may be socially better off in terms of local acceptance and social capital[16, 17]. Difference is often nuanced.

'…It's like a football team in [X place] now there's half the team could be settled people and the other half could be Travellers, but that's not everywhere like…in other places settled people wouldn't go near Travellers' (Men1).

The data reported that Travellers who are economically comfortable including some who occupy positions of professional or civic status experienced negative attitudes, discriminatory behaviour and hostility because of their Traveller identity.

'…And it goes back to the question, no matter how well you think you are, you could be a top businessman it all breaks out, you're nothing but a 'knacker' are ye' (Accommodation 1).

Discrimination and Social Exclusion

When Travellers talk they tend to talk about themselves in juxtaposition to the 'settled community' - a 'them' and 'us' dialogue that might be described as a dichotomous worldview, that of Travellers and non-Travellers. The focus group and interview data suggests that this is the result of regularly being exposed to distinctions being made about them from early childhood as different.

Discrimination emerged spontaneously as a commanding feature across the data. There was thematic prevalence and this was one of the first points of saturation spread across the Traveller and Provider data. While experiences varied, discrimination appeared to be constant and was reported in different contexts. Travellers perceive that they cannot successfully navigate their lives because of discrimination.

Service Provider data variously refers to Traveller lifestyle as 'chaotic', 'in crisis', 'frightened' and 'suspicious'. Traveller behaviour was affected by how they perceived they were discriminated against. In addition to expressing feelings of paranoia other feelings emerged from the data ranging from a sense of resignation and fatalism to black humour. Traveller men repeatedly reported low self-worth, low esteem, anxiety, depression and self-destructive behaviour.

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[16] Some Traveller families in the west of Ireland for example. See also Murphy village South Carolina.

[17] The idea of social capital may be sourced to Durkheim. These concepts however have been developed differently by Putnam (1995) and Bourdieu (1977, 1984)

Integration was discussed as an unattractive option by Travellers. The following narrative suggested that some felt compelled to make the choice involving quality of life (for their children) over cultural identity.

'…There's a lot of reasons for that and one of them is because of the stigma and the discrimination that Travellers suffer…the choice is not there for them so they actually do integrate and integrate on the basis that they're hoping their children won't suffer the same that they have suffered as they were growing up' (Men1).

Men and women reported that while legislation (the Equal Status Act (2006) ROI) had helped in some ways in terms of preventing blatant discrimination, they still felt marginalised, excluded and isolated so that discrimination was applied differently and more insidiously.

'...the racism is not as blatant as it used to be. It's a bit more sophisticated now. Like at one stage there we seen signs on the doors of picture halls and pubs, 'no tinkers, no hawkers', right. So the signs were taken down and then when you actually went to the door they were saying, 'We don't serve your type here. We don't serve Travellers" (Accommodation1).

Some perceived that modern lifestyle had left them behind and confused. The data also suggested nostalgic reference to better times and some narratives were highly critical of modernity and the effects of modernity for Travellers, their lifestyle and their culture.

'…It is just the view of settled people, now that has a lot to do with negative press and all of that kind of stuff, but the point is in the olden times people wanted Travellers around because they were a benefit for various different reasons, but now we are being looked on, as, you know, as people kind of on the outskirts, the fringes, criminals, the spongers, the likes of that, so I think it has gotten worse for us in a lot of ways' (Men2).

Others rejected the idea that Travellers were somehow 'behind' settled people. Some men had definite ideas of where they were located, pointing up a proud Traveller identity and culture.

'…I'm proud to be a Traveller….Better to be seen as a proud Traveller than a failed settled person' (Men2).

While social deprivation affected the settled community and Travellers alike, Traveller men talked about not wanting 'preferential', but 'equal' treatment.

'…To integrate with someone you have to be respected equally. This does not happen. We know people identify us as different. Settled people don't respect that difference' (Men2).

However, several advocates cautioned that equality should not be taken as integration but that equality within 'diversity' was needed. This was part of a required move towards intercultural approaches rather than multicultural approaches. The latter had a danger of exoticising Travellers, rather than responding to their needs.

'…Many people just don't understand what culture means and the difference between intercultural and multi-cultural approaches. But once they get it, they really get it and progress can be made' (SSI: Service Provider).

Travellers reported that they felt discriminated against and excluded in different aspects of Irish social and cultural life in ROI and in NI. They provided examples of what they saw as social, structural, state and legal discrimination. They perceived discrimination to be multilevel, pervasive and enduring. They talked about direct and indirect discrimination, that is, directly, such as putting Travellers' records last on a list or putting Traveller children to the back of the class room 'to colour in', or indirectly where the system is set up in such a way that Travellers cannot negotiate it effectively.

'…You see, it's one thing having an anti-racism Code of Practice in the schools but if people's attitude and prejudices towards any one community it is going to impact on the service they deliver to the community. As in the way that teacher will teach your child. That's what I mean. (Education 2).

It is now recognised that equality and diversity are central to promoting health gain and wellbeing. Aside from the moral, legal and social case for promoting equality, it also makes sound business sense[18].

Travellers said they found it difficult to associate freely in social venues. This sometimes resulted in social separation promoting unregulated and unpoliced alcohol consumption in back alleys and fields. It also has the potential to promote deviant behaviour such as drink driving.'*…Younger men they have it tougher.*

One of the dangers is that they are not allowed in local areas. They have cars and they are driving far where they mightn't be recognised and you are seeing it coming up a lot over the last year a lot more accidents, young fellas getting into road accidents…. Boys would drink at sixteen or seventeen… Like they might drive from x now to xx, they might drive from x to xxx they go farther they can drive down to xxxx, xxxxx and that's just for a disco they leave at 6 o'clock in the evening and you have the fear then of the parents thinking they are driving that late at night, there is no need for it when themselves is right at their doorstep and just because the Travellers can't use it' (Young People1).

Travellers also reported that they internalise the negative views and reports of them. It was also reported that some young Travellers were using settled terms of abuse against each other, calling each other 'knackers'.

Low self-esteem and discrimination were perceived as a main source of stress among men. Feelings of negative self-worth were reported as 'the biggest things' affecting the Traveller community.

'…We have lost our thick skin…' (Men 1).

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[18] See IDEA The strategic role of equity and diversity in health (www.idea.gov.uk/idk/core/pageid=17074663). Also The health needs of Gypsies and Travellers (www.idea.gov.uk/idk/core/pageid=17917440).

Some men interpreted non-Travellers, Government and health agencies as uncaring evidenced by what they perceived to be not necessarily a lack of services per se but a lack of appropriate services to the specific health need of Travellers even in the most extreme of circumstances.

'…I am a fellow that can stand up and fight my corner and so on and anything, but the thing about it is that there is people out there, young people, out there that wouldn't have the same self confidence. That happens to them on a regular basis, right, then they start believing all this. And those are the lads, they go out and they then, they hang themselves because they are saying we are reaching out to the settled community but they are not meeting us half way' (Men2).

Discrimination, 'Telling', and 'Passing-Off'

People's dispositions are also shaped by social and cultural conventions in society. These generate meaningful practices and perceptions. This involves identifiers such as surnames and language, dialect, accent, interests, dress code, gestures, even food preferences. The person carries social value in their demeanor and behaviour. Bourdieu (1977) refers to this as 'Habitus'. Travellers are differentiated by the process described by Burton (1978) as 'Telling'. This is a method (conscious or otherwise) of seeking to identify social and cultural difference between people (recognising or telling people apart) and in regulating behaviour accordingly.

'…Once you open your mouth…It would be in bars and in socialising, that's one area, I think, clearly identifying who you are' (Men2).

Some mothers told of how their child would change their accent and dress code and deny their identity in order to fit in and avoid being bullied. There were numerous accounts from both adult focus groups and from young people that told of children and young adults 'passing off' at school/college/work in order to avoid being recognised as Travellers (see Garfinkel, 1967; Rogers, 1992). Travellers said that they are easily identified because of their name, how they talked and how they looked and behaved. Depending on the context Travellers both asserted their identity and passed it off at the same time.

A further example included a young man being told that he couldn't be a Traveller because he was *'too stylish and smart'.* Yet, another young man who defied the stereotype in NI was told that he couldn't be a local man because he *'…didn't sound like one'* and must be from ROI (Young People 1). At these times Travellers said that they had to make a judgement call on whether to *'admit'* their Traveller identity or not. Either way there were consequences. At other times the discrimination was overt and involved multiple examples of being denied access to institutions and leisure/social facilities.

The narrative illustrated that Travellers who had more frequent or even intermittent contact with non-Travellers reported better social relations, for example with publicans and hoteliers. This appeared to be more likely in rural than urban areas but was not always the case as pockets of discrimination were said to exist and it was easier to be anonymous in a more cosmopolitan context. Men reported that the biggest problem they faced was social exclusion and stigmatisation.

'…It depends on the area and where you live. It depends on the past experience of that locality with Travellers. It depends on the neighbours as well…You know there's a couple of ways of looking at it, you can actually take it on a prejudice level where you go in and for whatever reason the bar person wouldn't serve you, or would be completely ignoring you from the minute you walk up to the bar…You know you become a second-class customer in the space of a few minutes. Having said that, you can also prejudge people very quickly and that person could be busy, something could be on their mind and you could automatically think that that person isn't going to serve you' (Young People1).

Older and younger men agreed that they felt discriminated against socially and said they often regulated their behaviour to get access to social and recreational facilities.

'…Well some of the pubs you go in and they actually turn around and say they are not serving you know' (Men 1).

*'…If there is a lot of people in hotels you can't get in there either' (*Men1).

'…You are excluded from on a Friday or Saturday night. These are the nights that you decide to enjoy socialising' (Men1).

'…Well, sometimes you go to the bar drinking and there could be other Travellers that you'd know walk in and you can't talk to them. They can't come up around you, 'cause if they come over, then you can get barred and they get you barred and you could get them barred and all that' (Men1).

'…When you are in public you can't talk out loud…you're whispering' (Men1).

There is therefore a tendency to congregate in small numbers. These behaviours may themselves add to distrust and stigmatising of Travellers enhancing suspicion and promoting a cycle of negative stereotyping.

Dressing Up and Dressing Down

Young Travellers also hid their identity to get access to basic social facilities.

'…I have seen young girls glammed enough that they could walk on the red carpet in Hollywood and they are not let into the pictures' (Young People1).

'…When you go any disco you had to change their identity. Take off earrings, change your hairstyle, had to get some clothes off a settled friend to get in. Then they say, 'do I look Travellerish in this?' and it's like, that's too Travellerish, take it off, tie down your hair!' I have seen Travellers girls put on glasses' (Young People1).

'…Traveller girls will dress down to get into a disco, but they don't take on settled person's ways' (Young People1).

The data illustrated how discrimination affected Travellers socially, psychologically and materially. Travellers thought that 'telling' affected their ability to get access to things such as car insurance, hire purchase, loans and white goods. This left them open and vulnerable to loan sharks. They also reported having to pay more for example, if they needed to hire equipment or venues.

The focus group narrative recounts numerous occasions where Travellers perceived discrimination. This included name-calling, bullying and exclusion within schools (classroom and playground), employment disadvantage, to treatment and services in healthcare. Individual and antisocial behaviour is reported as a feature of both the Traveller and settled community.

There was thematic prevalence in ROI and NI on Travellers hiding identity to get access to employment, and leisure. Travellers reported changing accents and giving different addresses.
One Traveller stated that, *'…if there is a problem with a Traveller then all Travellers are stigmatised…If something happens on the news you just say to yourself, I hope to God it's not a Traveller'.*

'It is sometimes reported that, following the establishment of Gypsy and Traveller sites, there will be a rise in anti-social and/or criminal behaviour. While there may be individual elements in the Gypsy and Traveller community that may be involved in such behaviour, there is absolutely no substantive evidence that the level of such behaviour is any more significant than in other groups, or in the population as a whole. However, the reporting of cases where such activity does take place can sometimes lead to a misconception that all Gypsies and Travellers are involved in criminal or antisocial behaviour. That is not the case at all. Indeed, Gypsies and Travellers are often the victims of such behaviour, or at the receiving end of racist behaviour or language' (Communities and Local Government 2009:15).

Living and Working Conditions

Socio-economic Position and Health Chances

As we outline in Technical Report 1, a health determinants approach is fundamental to our understanding of Traveller health. The World Health Organisation provides a useful outline of determinants of health:

'…The social conditions in which people live and work can help create or destroy their health. Lack of income, inappropriate housing, unsafe workplaces and lack of access to health care systems are some of the social determinants of health leading to inequalities' (World Health Organisation, 2004).

Competing explanations for health inequalities are presented elsewhere[19] . The All Ireland Institute of Public Health has produced a series of reports on health inequalities and their determinants across the island of Ireland, complementing a widely established international literature (Balanda and Wilde (2001, 2003)). More recently the work of the Health Research Board-funded unit for health status and health

[19] Moore and Harrisson (1995), Solar and Irwin (2007) review of the literature.

gain (Kelleher et al., 2007) clearly establishes that significant health inequality exists in Ireland. A review of health inequalities in ROI and NI was recently compiled (see Farrell et al., 2008).

Health and life chances are affected by multiple layers of influence, and this is no different for Travellers (see for example Farrell et al., 2008). Technical Reports 1 and 2 deal quantitatively with the current evidence in relation to Traveller health in addition to socio-economic lifestyle, poverty and social deprivation, cultural preferences, support networks, services, mobility and attitudes, such as positive or negative regard also impact on Traveller health. In the case of Irish Travellers, culture of poverty explanations advocated by McCarthy (1972) have largely been revised (see McCann et al., 1994). Lifestyle choice and behaviour carry considerable significance but health chances appear largely to be determined by factors beyond the control of Travellers themselves. Much of the literature points to material/structural factors as crucially important health determinants (see for example O'Connell, 2002 on this issue). The majority of Travellers in Ireland continue to live in reduced economic circumstances.

Work and Unemployment

The change from agrarian society through to the various phases of industrialisation and modernisation meant that traditional Traveller employment became increasingly marginalised in a skilled and mechanised labour market. While historically the industrial phases in Britain and NI, contrasted to those of ROI, Traveller narratives in ROI and NI were markedly similar[20] . Industrialisation and modernisation (including factory and mass production, globalisation and world markets), meant a move to a more highly structured economic base that left many traditional Traveller jobs and skills (such as they were) redundant. The advent of plastics and mass production were to be symbolic of major change for Travellers and their way of life. Travellers' accounts outlined how employment, work and way of life have changed in a very short timeframe, indeed within living memory.

'…Whereas now with the plastic and machinery Travellers are actually not needed. They are more feared now than they ever were. Like this woman said here, years ago you would see the settled people opening the doors for Travellers' (Work).

Historically Travellers are thought to have played a significant role in the Irish rural economy. Fanning (2009) offers important narratives from Travellers detailing lifestyle and describing the range of Traveller occupations prior to the 1960s. Travellers traditionally worked as artisans and entrepreneur traders often in non-apprenticed trades. Travellers were self-employed independent units based predominantly around the extended family and kin (Fanning, 2009).

'…Family is very important to the Traveller community and family links, whether you're in England or Ireland. If there is something happening within the family it involves all the family rather than the individual unit themselves' (Young People1).

[20] ROI industrialised much later than the UK and NI and moved quickly into a phase of hi-tech, high spec industries.

The data indicated a preference to be socially and economically independent. This preference necessitates close cooperation with extended family and wider kin. Therefore the family nexus was central economically as well as socially and psychologically. Marriages were traditionally arranged and endogamous. Herron et al. (2000) and Greenan (2009) also document the centrality of the family (economically, socially, and psychologically) to Travellers.

A weakened job/skills base was a major barrier to traditional forms of economic independence (and culture) of Irish Travellers. Seasonal economic rhythms and dispositions gave way to clockwork, punch cards, and later quartz and digitised regularity. The collective memory of Travellers laments these changes.

'…We did seasonal work, potatoes, the harvesting, the hay, the whole lot, even the turf and tin smithing, or whatever it was generally, rearing horses, breeding' (Men2).

Change was frequently recounted in discussions with Traveller men and women. Rites of passage and cultural markers are said to have changed.

'…They're taking our culture away from Travellers which then leaves them to get involved with drugs. No pastimes, no employment' (Accommodation 1).

'…There is a lot of stuff happening within Traveller culture at the moment, and I can see it happening. It wasn't what I was brought up with' (Men1).

'…My worry is our younger generation, and you see because the Traveller economy has changed, our culture is being taken away from us bit by bit, sort of every 2 or 3 years. The laws that have come in place say the last ten years. You see a big part of our tradition was horses. Horses was sort of a marker to a young son who was getting married at seventeen, eighteen or nineteen years of age – that has been taken away from us. Now it is the fast car, do you know what I mean' (Addiction1).

Often the broader determinants were discussed in the context of discussing employment, for example, education and discrimination.

'…I think to look at employment it has to look at all…wider than just employment. You know the education and all that has to fit into it. But also to acknowledge the work of the Traveller organisations. That there is role models within them organisations' (Work).

The funding of Traveller organisations and Primary Healthcare for Traveller Projects (PHCTPs), see Technical Report 1, were seen as a major positive step as they provided employment, helped to build people's confidence and produced role models for younger members of the community in an environment where it was not necessary to hide their identity. Training centres were more contentious in that both positive and negative aspects were reported. While in the main Travellers felt that they opened up doors to education when school was not seen as an option, on occasion they also reported

that getting paid through training centres had in the past led to early school leaving with little outcomes or opportunities in their view for employment.

'…You have got people who was in training centres for the last 10 to 15 years and who can still not write their name' (Accommodation 2).

Some of the recommendations made in the focus groups included positive action such as internships, though only if progression to long-term employment was a potential outcome and tackling discrimination in order to promote Travellers looking for jobs in mainstream employment. Such opportunities should include both Traveller men and women.

Discrimination and Employment

Employment was an important arena where discrimination was perceived to be commonly encountered.

'…If you identify yourself as being a Traveller you are not going to get employment, now' (Men2).

'…I think there is discrimination with Travellers in Ireland some Travellers is like…do you remember black people back in the 1950s and '60s law, that is what it like, that kind of discrimination' (Work).

'…Like I think there are an awful lot more options for women available to go out and work where men can't' (Men1).

Many Travellers reported that after leaving school, training was an option but did not always lead to employment opportunities.

'…The only thing about now…now say the boys they are going to school now and getting on like at the X course. They are getting the training with that like. But when they have it all and got finished at the apprentice they still can't get a job' (Education 1).*'…Do they get jobs when they leave [Education 1]. No, because unless they change their name on the form'* (Education 2).

Several Traveller men were concerned that formal work would compromise them economically, via loss of benefits and medical card (ROI). Travellers also discussed the consequences of new communities competing with them in the job market[21].

'…Even work, you are treated differently when you are looking for a job…a person from X [country] or whatever and you know well…you are better at the English language but they are more or less going to get the job before you. It's no good saying you are better than anyone going in to get the job no matter what age you are, no matter how much education you have. If you are a Traveller you are going to be discriminated against' (Men2).

[21] During the 1990s ROI established itself as a major magnet for high-tech (mostly foreign) businesses and peripheral industries. This was believed to produce what was called 'the Celtic Tiger economy'. As migration laws within Europe relaxed this attracted considerable foreign labour particularly from former East European but also African and other countries.

The focus group participants talked about hiding their identity when going for a job. Informal work if available could supplement a meagre income, but Traveller men reported that in addition to being discriminated against in the formal economy they are also excluded from the informal economy such as labouring, or gardening for example.

The perception was that foreign nationals and other minorities are treated better and they settle and *'…are seen as locals within a year or two. Travellers will never be local'.* (Men 1)

Education

Education was identified in the data, by Travellers and Service Providers, as of key importance. The issue of low education achievement was viewed as a major barrier to improved lifestyle and health and in urgent need of redress by both Travellers themselves and Service Providers.

'…Education, education and education are the three most important things, both standard education of the community and education in specific health matters' (SSI: Service Provider).

The negative effects were reported to begin in early childhood (as early as 3 years old) and to continue throughout the lives of Travellers. These effects were perceived to involve broader issues than literacy and knowledge gained through normal schooling. The data reported the importance of education or lack of education on wide ranging social, cultural, psychological and economic factors. These affected self-esteem, and confidence of not just the child but the parents too.

'…the more confident the parent, the more confident the child' (SSI: Service Provider).

Some young Travellers indicated that they wanted to stay on at school at least until they reached their Leaving Certificate and some said they wanted to go to college or university. Aspirations included being a gardener, an out-in-the open job, a guard, joining the army and being a beautician, going to college and getting married. For some girls an early marriage meant that staying on at school was not a priority in their lives. They eagerly anticipated settling into the prescribed gender role as soon as possible after 16 years of age. This was expressed as a way to become independent from family ties and to gain more freedom. However several narratives during the focus groups suggested that this may be overly optimistic in many cases and is borne out in the data throughout.

'…At the time all the girls was leaving at 13 and you were helping out at home' (Education1).

The data indicated that there are multiple factors that appear to overlay each other resulting in poor attendance for some Travellers and an early leaving age for many.

'…They still have to face discrimination and you can see a bit of difference now. Hopefully it will lead into the future when they do pass all their exams and that, 'cos there is a few young fellas going for their Junior Certs and I think there is one young fella coming up for Leaving Cert in the X area' (Education1).

'…In trailers like it is hard for a child to do their homework' (Education1).

Historically, nomadism was seen as counter to the needs of regular attendance at a given school. The move towards living in houses was encouraged by State policies in an effort to assimilate Travellers via the education of Traveller children. However, the data reported that many of the families appeared to value educational opportunities for their children and wished for them to reach higher levels than they had themselves. Travellers pointed to the assimilation process as not solving the problem.

'… always bad attendance. That is the one issue which it isn't always the case. I mean I know a lot of Travellers that is going to school and is getting trophies or whatever for missing no days and they are still coming out with no education. So there is a problem somewhere' (Education 2).'

'…I had education, but my parents didn't have education so I was going in there with parents who didn't read and write but the settled community for generations their parents and their grandparents were able to read and write, so we do want to be equal but yet we do have to learnt a different way' (Education 2).

Travellers perceived that some teachers also discriminated against them. Traveller children were said to look up to teachers but Travellers perceived that it was the teachers that were *'putting them down'* (Education).

'…Slow learners, like I got put into a room with the teacher fixing jigsaws and I got put into the slowest class in school. Slow learners every one used to call it. And I got put into that like automatically without even doing a test. And just putting me down like' (Education1).

However, there were also some positive reports about good teachers and Travellers having settled friends in secondary school.

'…A lot of schools now has homework clubs where the children can wait and do their homework, that's good' (Education1).

'…She [the teacher] said X tells me that his daddy and mammy can't read and write, so in ways I can't give him homework because there's no one at home to help him' (Education 1).

Older Travellers offered accounts of being made to sit at the back of the class, being given a pen and segregated from the rest of the class.

'…Making you feel different and making the other children see you as different. Teachers were letting people know you were a Traveller' (Education2).

'…You were a Traveller. You were nobody' (Education2).

'…Schools have changed over the years but there is still stuff going on in schools that is actually worse than what happened in our time' (Education 2).

There were also some who felt that they still *'…put them [Travellers] at the back of the class'* (Accommodation 2).

The need for young people to hide their identity was repeated in the context of both school and employment. It was voiced as sometimes necessary in order *'…to get ahead'* but the consequences on mental health of denying their identity was recognised by many Travellers and is confirmed in the literature (Thompson (1999) in Mind, 2010).

'…You have to live with the pressure of hiding your identity' (Education2).

'…I know a young girl that when she went to school and never classed herself as a Traveller and went on and had a brilliant job and never came out and said she was a Traveller but the abuse that she had to listen to every day from her manager [about Travellers] that at the end of it she couldn't take it and she just left and he still didn't know she was a Traveller' (Education2).

'…A lot of Travellers now are fighting the fact that they are Travellers and it's not because I don't…. they are ashamed. They have no choice because if it comes out that they are a Traveller everything changes' (Education2).

The data indicated that the negative effects of the educational experience impacted on self-confidence and resulted in people not *'…being confident enough to stand up'.* The effects were said to have lasting consequences as many, indeed most, recounted having *'…an awful time'* at school and *'…low self-esteem, low confidence'* which still lingered today. A young male Traveller told of how it took years to shake off the negative effects of school and name calling and begin to have confidence in his own worth and ability. This resulted in a situation where *'…leaving school did not feel like a choice'* but rather a necessity.

Bullying, name-calling and fights at school loomed large in most of the descriptions of school life, from both young people and their parents. When two separate groups of young people were asked during the participatory research what would you most like to change about being a Traveller (having also been invited to suggest what they most liked) they unanimously said, *'…being called names'.* It was a subject they raised many times and a reason why they most disliked the school experience (Participatory Research with Young People: Urban and Rural).

However, there were exceptions:

'…but I have to say my own children are not suffering that. They love school...' (Education2).

Communication between school and parents also varied. Suggestions for improving the situation included, intercultural days in school for the children and anti-racist training being included in in-service training.

'…I think bullying in school should be an anti-racist done with the children before they go into secondary school. School don't deal with it like I think she should deal with it because they are Travellers they are actually picked out' (Parental perceptions of child health services).

Bad experiences in school tended to make participants all the more determined that their children would have a better experience and many participants spoke of the importance of encouraging young people to stay in education. At the same time, it was perceived that Traveller men find it much harder than Traveller women to gain employment, thus the disincentive to stay in education.

'…I think parents know if they have a good education themselves and they know themselves and they know what their families have been through...through school and they don't want their children getting the same experience. They want their children to go on and get a good education' (Education 2).

'…I think it is, you know what I mean 'cos there is an onus on the boys, you know what I mean and sometimes within the family structures that the boys leave, they want the boys to leave which I think is totally wrong, the boys should be kept on just because they are a boy doesn't mean that they should have to leave school, you know, and in the structure of the travelling community this has to change as actually the education part of the children, right, and I know a lot of our families now there's more onus on education because people see education now as, you need it. Anywhere where you go now you need education, when you get insurance for a car, when you get insurance for anything you're doing the house, you need education you need to know how to write and read. You know you need papers going for passports you know, it's all changed from years ago, people thinking maybe 20 years ago you mightn't have needed the education 20 years on you need the education now you know what I mean' (Accommodation 2).

Education attainment appeared to be related to employment aspirations, securing paid work and economic security. In addition a lack of education also impacted on the ability to understand, be aware of, and navigate the range of social and health services effectively.

This is set against a backdrop of few role models, little history of Travellers staying in education or working outside the Traveller economy. Many of the young people indicated that there was very little point in staying on at school because there was no chance of gaining paid employment afterwards because of discrimination.

'...my second youngest said to him one day, 'You are not leaving school at 16' and he said back to him, 'you did your Leaving. You went to college. Where did it get you? You are at home on the dole" (Education2).

One Traveller reported that a good school principal had encouraged a child to go to college. But the same Traveller questioned the use of college education if there is no job waiting for them.

Adult education and the value of Traveller organisations, PHCTPs and training centres were recognised throughout the focus groups. As mentioned earlier they were seen as an alternate route through education when conventional routes were not seen as an option. In addition, Traveller groups were often reported as having helped encourage Travellers to build up their confidence and self-esteem and this in turn helped Travellers have the confidence to ensure that their children received a good education. Not having a Traveller organisation in the area was often noted as being a distinct disadvantage.

'…It was just the scenario at the back of the class with a pen, a blank page and colours. That was my daily routine, and as I was going… progressing through school I was never encouraged or supported to go any further so I left early in schooling and I had to look for other pathways to get further education and that would be through Traveller organisations and up skilling myself that way' (Education 2).

'…And I think once you are involved in an organisation or the likes of a training centre there is more doors open for adult Travellers to go on to further education if they want. But there is a lot of Travellers that would be...wouldn't be involved or know organisation in their areas that still would feel isolated' (Education 2).

With only some exceptions, Travellers generally saw segregated education as being unacceptable. However, it was perceived that the school curriculum needed to be more explicitly inclusive of Travellers and their culture and this might mean directing more energy to affirmative action.

'…If they are going to teach the culture it is also going to break that stigma. That's between the settled and the Travellers. It'll let the people know that we are not aliens' (Education 2).

The Advisory Committee on Traveller Education presents an important forum to monitor, assess and provide for engagement of Travellers in a structured and coordinated way. This could for example focus on integrating Traveller only education into enhanced mainstream provision for Travellers. This should be needs based rather than identity based, in order to respect cultural identity of Travellers on a par with citizens from other ethnic minority backgrounds. Such an approach is likely to enhance the educational experience for Travellers and in addition social capital (bonding) experiences with non-Traveller children. An education expert stressed the importance of cultural diversity.

'…There is no such thing as an intercultural curriculum, it is not a subject; it has to saturate the entire curriculum, it is an approach...' (SSI: Service Provider).

'…Diversity is normal, and normality is diverse...' (SSI: Service Provider).

Since 1998 the éist project[22] has advocated and promoted the inclusion of a comprehensive approach to addressing Diversity and Equality in the Irish Early Childhood Care and Education (ECCE). This focuses on the respect for differences in ECCE and has influenced early childhood policies, practices and

[22] éist project: further information is available at : http://www.paveepoint.ie/progs_child.html

training in Ireland. The strategy is influenced by a number of working documents and reports including the Expert Working Group on Child Care (1999), Diversity and Equality Guidelines for Childcare Providers (OMCYA, 2006) and the Intercultural Education Strategy (forthcoming).

There needs to be realistic expectation of education attainment of the Travellers, and there need to be multiple approaches simultaneously improving children and adult education, yet with realistic goals.

'…education attainment level among the Irish population as a whole in say in the '40s compared to the '90s there is no comparison; and it took us from inception of the national school system from the 18th Century, or 19th Century it was, it took us a century and a half to get to here and now we are wondering why the Travellers can't do it about 5 times as fast?...But they have to do it 5 times as fast, they have to run while we walk, there is no choice in the world today…' (SSI: Service Provider).

Accommodation

Good-quality, affordable, safe accommodation is essential to our wellbeing (United National Human Development Report, 2004:Chapter 3)). It is axiomatic in public health terms that physical health may be influenced by living conditions. Poor housing or homelessness can also contribute to mental ill-health or can make an episode of mental distress more difficult to manage. This may also be compounded by the fact that poor housing and homelessness are often linked to other forms of social exclusion, such as poverty (Mind, 2010). In Technical Report 1 we present the different types of accommodation that Travellers occupy in both ROI and NI. The participants in the focus groups experienced, and spoke of, this spectrum. Some were living in houses and some in halting sites. Accommodation was cited as a key problem for Travellers and emerged as an important theme in many of the focus groups. However, provision and experience are not uniform between ROI and NI or between regional areas. Both users and providers recognise a need to improve both the level of accommodation provided and its quality.

Data from the focus groups suggests a complex picture relating to accommodation. The Traveller community is not a homogeneous group and consequently expresses divergent views on what represents optimum housing solutions for different families and experiences of using relevant services. However, they have a uniform opinion that better accommodation is required. In many cases, accommodation impacts, directly and indirectly, on health and wellbeing.

'…Do you know, but it's 10 kids down there, there's a small baby and everything. Do you know if it rains, the muck is in the door. They're living in a muck pile' (Accommodation 1).

'…And these are people who have moved into standard housing that are being isolated and suffering from depression. Do you know what I mean, the council think they are doing a good job now? Put them in standard housing. They've been isolated from their extended family, do you know what I mean?' (Accommodation 1).

'…They are just forgotten about' (Accommodation 1).

Travellers reported that their moods, mental and general health were also affected by living in poor accommodation and poor environments. The threat of a disappearing nomadism continues to be a relevant factor for some Travellers, with a perception that legislation[23] , particularly more recently, has created a situation where the option of travelling is more difficult to achieve and is reflected in declining numbers of Travellers who regularly travel.

'…So they have wrapped that Traveller culture piece up in so many ways. They've tied it in knots and trapped, they've made it impossible for Travellers to move around. And forget about transient sites because they will do the same thing with those' (Accommodation 1).

However, a lack of travel does not equate simplistically to a declining wish to travel for many. Travel was regularly invoked as a defining characteristic of being a Traveller and part of the Traveller identity, as previously discussed. This links back to ideas of assimilation via living in houses rejected by Travellers. It is instructive that Travellers make a clear distinction between the settled community and themselves as a *'…Traveller living in a house'* rather than being settled. It is a clear, symbolic, verbal separation and rejection of assimilation. This appears to invoke the notion that to move on is a desired option and it is an important consideration for successful accommodation policy to recognise this according to the data.

'…I am a Traveller and the fact that me children have never lived in a house is one thing about them. Like even though they've never travelled a day in their life, they're still Travellers' (Accommodation 1).

The more nomadic groups report that they frequently have to privately rent housing when they are not travelling. They often have no other option if they are not to be homeless. The data discusses legislation which makes being nomadic difficult, specifically the indigenous clause and the 2002 Trespass Law in ROI (see footnote).

'…They've made it impossible for them to move around, and now with this Indigenous clause, you can potentially make yourself homeless' (Accommodation 1).

By common consent, the best sites in NI have been achieved through consultation with Travellers from the outset. These typically either offer space for both a caravan or trailer as well as a house or a caravan or trailer with a hub built alongside which provides for individual bathroom facilities, cooking facilities and laundry facilities. In some instances, this has even included provision for horses nearby. However, such pilot schemes are examples of best practice according to both Travellers and Service Providers and do not represent the more general experience of the majority of Travellers.

A Traveller from ROI gave an example of what she considered a good site, which matched the NI experience:

[23] This refers to the Housing (Miscellaneous Provisions) Act (2002), which makes trespass on land a criminal offence and allows Gardaí to arrest without warrant, hence known to Travellers as the 'Trespass Act'.

'…A good site, it was only open at the time 6 months and it had houses on it and it had day units. The houses obviously, they had four bedrooms in them. But for those who wanted to still live in a caravan, they had a unit with toilets and kitchen facilities and what ever and they also had a bay. And that's what you call good accommodation' (Accommodation 1).

Examples from the other extreme include what have been referred to as *'…third world'* conditions on some serviced sites and facilities which require serious updating on others.

In addition to the many examples of existing inadequate provision on serviced sites and the need to upgrade many of these, there is also a need to identify and provide more transit sites. This was confirmed by an accommodation officer when the difficulty of finding a site was highlighted at interview and discussed at length because of discrimination against Travellers. There is agreement on these needs by both the Traveller community and Service Providers. There is also a need for more group housing schemes and accommodation in mainstream housing which have again been recognised as needed by both Travellers and by statutory agencies. In short, more good quality accommodation is needed across the island and across the types of accommodation preferred.

There is a perception by Travellers that legislation and guidelines are frequently not being translated into action and are being paralysed by local councils, planning groups and some politicians and by the settled population via the NIMBY (not in my backyard) phenomenon with the general population when sites need to be identified and built. Again, this spans both ROI and NI.

'…The guidelines are there but the guidelines are being abused at local authority level' (Accommodation 1).

'…There's 10 commandments as I was taught. Grew up in life as a Catholic, but there's a level there when it comes to Travellers. And that level is love they neighbour as long as you're not next door, and that's exactly what's happening. The very minute a halting site is mentioned, there's like a panic and all of a sudden you have these business people, you have neighbours, you have councillors' (Accommodation 1).

This is borne out in the data by Service Providers when Traveller accommodation needs were being considered and agencies involved in discussions with Service Providers perceived that there were a large number of Travellers in one area and wanted to,

'…spread them out like butter' (SSI: Service Provider).

The data suggests that there are combinations of factors that cannot be reduced to any one institutional actor or agency but which nevertheless translate into a difficult context for improvement. There is a perceived need for discrimination to be tackled at institutional level on this particular issue. Consultation was recognised as crucially necessary by both Travellers and Service Providers. At its best this worked very well and was outlined by both parties and acted as a model of good practice. Travellers worked closely with housing authorities from the outset resulting in the Traveller families involved having their needs met. However, there are countless examples when this was not the case, hence the need for consultation at early planning stage.

'…A really nice, well-run halting site. I've seen some good halting site' (Accommodation).

In ROI, mainstreaming of accommodation was seen as necessary, as often Traveller accommodation needs were segregated from the general population. Travellers found this discriminatory and felt it resulted in them feeling uncomfortable and easily identified as different in the offices when attempting to progress their needs.

A lack of homogeneity extends to finances, with some Travellers experiencing poverty and lack of choice. In cases of poverty Travellers suggested that if a loan scheme existed it would allow them to buy a trailer or group housing. To mention poverty does not by any means convey the depth of the data and the too numerous to quote hardships discussed involving evictions of some very vulnerable families in some parts of the island.

Evidence of good practice extended to a change from communal responsibility to individual citizenship when each family was given an electric meter for their own individual facilities. The scheme had worked well to everyone's satisfaction including the electricity board and a spin-off effect meant that families were given their own postal address for billing purposes which had knock-on effects for health, as it improved contactability for service access. There was a clear and universal realisation from Travellers that accommodation status impacted on isolation, depression, social support of family and childcare options.

Travellers are concerned also about living away from close family and among those who see them and react to them as deviant and alien. They are concerned also about the consequences of prejudice and stigmatisation. Cases were recounted where residents (NI) held protests against Traveller families being placed in social housing.

Some Travellers talked of having their door locks glued, of paint being thrown, of their house being flooded, of local petitions set up to call for exclusion of Travellers from their locality and street. This occurred in both ROI and NI.

In addition to a cultural commitment to nomadic lifestyle, Travellers also pursue rational choice:

*'…Some wouldn't settle in houses. They like their freedom going around like' (*Men1).

There was major concern about the consequences of moving into settled accommodation.

'…The support structure is there to the extent that if I'm living on a halting site and my mother is living in a house or she is living nearby. I'm always around, but I think the thing with Traveller families is as soon as you open your eyes in the morning you open the door its like, do you want a cup of tea? It's like you're living in each others pockets 'cos that's the way Travellers want it, that's the way that they had it all their life. If I'm going to the shop I can shout across to X, X will you keep an eye on my small fella. You have that sense of closeness or if I was feeling ill with the flu I could shout out to XX. I'm not feeling very well will you just get them for me? You have that very, very strong support. When you're in a house you haven't got that' (Young People 2).

There is significant evidence of decreasing numbers of Travellers on halting sites and increasing numbers of Travellers living in permanent accommodation. This is confirmed by the literature and the census data presented earlier (Coates, Kane and Treadwell Shine, 2008:32).

'…They're trying to stop the culture like and they take them away [halting sites] as if they never existed and instead putting them down as settled when they always being travelling around everywhere' (Young People 1).

The data indicated that some Travellers had positive experiences particularly if they were housed with or near other Travellers in social housing. However this was not the case for most.

'…I am saying, even about people accepting people into housing estates like I know most of us would have a fairly good experience you know, but not all Travellers have the best experience' (Men2).

'…Luckily enough, where we are up there, all my neighbours are Travellers like. Nobody asks questions, they are good neighbours' (Men2).

Environment and Health: Basic Services

There was concern about environmental issues. The physical environment concern frequently expressed was about the lack of basic facilities and amenities, including play areas. In terms of halting sites there was a variation in experience, some were regarded as good and some bad. Halting sites were often far from shops and amenities. The data suggested that Travellers considered halting sites to be overcrowded. They also reported that there were long waiting times for suitable accommodation. Those in the most extreme circumstances said they felt forgotten about.

'…When you are put on a halting site it's like you are forgotten about' (Accommodation 2)

Major problems included lack of water, insufficient hot water and drainage, poor or no refuse collection, and problems with flooding and sewage. Damp and water ingress were reported to be a constant problem.

'…We have a hot water immersion but it doesn't last' (Young People2).

Travellers reported that when they had problems such as no water, they often had little success when trying to contact Accommodation Officers. When they did establish contact the officers in question were said to have little or no knowledge of their area. Some in ROI reported a lack of consultation on maintenance decisions and improvements problems and a lack of maintenance generally on the sites and frequently a lack of power supply often lasting for several days. This had knock-on effects for day-to-day living of the entire family; schooling, for example. There appeared to be a need for clearer pathways to communicate with appropriate accommodation services.

Electricity cards were expensive compared to mains electricity and quickly ran out. Some reported that only three sockets could be used at any one time. Water was also reported to sometimes be at low pressure and to work in one caravan at a time.

'…There's grease, black water and no heating so you have got no insulation. I know one of the main problems for women of our age myself and well I'm a bit older than X … It's kidney infections, severe kidney infections constantly and that's where sometimes if you're living on a site you might have to share antibiotics, that would be one of the symptoms of kidney infections you can't stand up or nothing' (Women1).

Women in particular perceived health threats from the local environment. There was considerable worry about dangerous sites. Embankments, power lines, electric transformers, emerged as important points of health concern. Women talked about cases of infections in children. This was confirmed in the Service Provider interviews.

'…The children often arrived with poorly developed social skills (playing and sharing), below expected fine-motor skill, not able to do jigsaws for age appropriateness… the children were reported to have asthma, chest infections, with passive smoking thought to be a key factor' (SSI: Service Provider).

There was concern also about local hazards, such as exposed electric mains cables as well as dangers in living beside busy roads. Travellers, for example, reported walking on dual carriageways. Also reported were seasonal issues such as poor lighting especially in winter. There was a high thematic prevalence regarding the disposal of rubbish and fly tipping. In addition, personal discomfort was discussed which affected young, old and disabled alike.

'…We would have to walk out of the cabins over to the shed to go to the bathroom. There's no heating' (Young People2).

Other concerns included rat infestation. Some men used rat poison, others used (pet) dogs to kill the rats.

'…You would be sitting inside and there would be rats running up and down the wall and you give no rat poisoning or nothing you would have to let the dogs out and then dogs eat the rats, like one dog came into our house with a rat in his mouth like' (Young People:1).

Lifestyle, Gender and Generational Change

Civic Engagement - Women's Experiences

Although experiences are individualised there continues to be a strong gender culture emphasising important differences between the lifestyles of men and women. Traveller culture is characterised by proud patriarchal dominance. Men were responsible for the family. Within Traveller culture it is the duty of the wife and children to be loyal to the father and women to obey men in the family [24].

Traveller women historically tended to marry young. Marriage is almost uniformly endogamous. In the past, weddings had been arranged or quasi-arranged. Young Traveller women were expected to be around the home assisting with households and domestic tasks. The data strongly indicated that women acted as managers of health and healthcare within the domestic setting. Women reported that they often subordinated their personal needs (including health and food) to those of the family, particularly children. Modesty and the chaperoning of young girls until marriage was considered important. Deviation from these strict cultural codes (for boys and girls) was regarded as an affront to the family and wider community. Shame was to be avoided at all costs. Some Traveller women reported that more girls appear to be marrying at an older age (around 19) in ROI but younger in NI where marriage is legal at 16.

During the participatory research with young people, the girls were invited to perform a devised performance (roleplay) making up the narrative as they went along. The performance they decided upon was one where a girl was seen by the group to be mixing with boys. The rest of the girls gathered around whispering about the other girl and shunned her as she tried to join their group. She was told to go away from them. They acted out the need to be beyond moral reproach and needed to separate themselves from her. To use their own words, to avoid being *'…scandalised'*. Immediately after the role play a member of the team asked if the term was used regularly and the girls assured her that *'…scandalised'* was commonly used and fully understood by everyone in the community. In other words, common parlance and culturally understood (Young People's Participatory Research: Rural). The data suggested that mothers, young families (and young women) tended to stay in and around the home (roadside, caravan site or house). Despite some broader changes this appears to remain the case as evidenced from the young people's participatory research data. Wider civic engagement was therefore limited.

Both the rural and urban research with young people evidenced that it was the cultural norm for girls to help with domestic chores. This came to light when both boys and girls were asked to describe what constituted a normal Saturday morning for them. It was also played out via roleplay, as the girls swept the floor, washed the windows and peeled potatoes to show the types of domestic work they took responsibility for.

[24] Boys of 16 years of age, (sometimes younger) were considered as men among Travellers.

Some young women reported that they occasionally socialised with non-Traveller friends from school but these opportunities were extremely limited. Women reported a tendency not to socialise away from the home. Social mixing, particularly for women, was usually tied to the immediate environs and family. Some women talked about drinking alcohol at home and watching television and that there was '…*nothing much to do*.' This lifestyle meant reduced chances for cross-cutting (bridging) ties[25].

This was borne out in the service provider interview data. A GP for example, commented that over the past year or so he had noticed a change. Traveller young women of school leaving age and older, not settled young women of the same age, were presenting at surgery with what he termed '…*dysteria*' (unhappiness) (SSI: Service Provider). It was as if having left school the protection had gone in terms of social contact and with few prospects for education or employment the girls had become socially isolated at home with nothing to do. He thought that the tendency for some to marry later was compounding the problem.

This tendency towards a more encapsulated lifestyle, with fewer opportunities to interface with other people, both Travellers and non-Travellers in the locality, thus limited such things as information exchange (considered as important for health information) as well as broader life enhancing activities.

Women reported that in the past there was a much stronger sense of community, where they were able to keep in touch with families and extended families more. The narrative also indicated that the reduction in travelling meant in some instances a narrowing of ties with family and friends. However many young Traveller women reported a commitment to Traveller culture and lifestyle, though a change in terms of value orientation and lifestyle was also noted[26] .

'…*I'd say that over the 5 years is after changing drastically with young Traveller girls. It's all clothes and cars. Young Traveller girls from their parents have never had it so easy, it's all about style, sun beds hairdos clothes…It's all about glamour*' (Young People2).

Contact and support from others outside the Traveller network was considered important and meant a great deal to many Traveller women. This had both manifest and latent functions. Some women for example, worked as Traveller Community Health Workers and the data suggests that women highly valued social contact, social networking, information exchange, and social separation from the home. This not only afforded health information exchange but also allowed women access to a range of broader information and life-enhancing experiences.

The experience of older women evidenced that the domestic sphere and family responsibilities continued to dominate many Traveller women's lives.

[25] See Putnam (1995).

[26] In her account of Irish Traveller lifestyle Helleiner (2000) locates social change from 1960s. However, change appears to have become increasing evident through successive generations from this period.

'…There's a lot of women in , older women, over 50s and 'em they really don't look after their own health as much as they should – they're always kind of looking after their children and their husbands, they never care for theirselves' (Older Women).

'…Women didn't look after their health in the olden days. The women didn't have time to look after their health because women had to go – there was one time there was no money or no income at all and there was no courses for the women like what we have now and including ourselves we had to go through the houses and had our call backs and sell pegs and sell things to make a better income to feed the children and women hadn't the time' (Older Women).

However, for some women change was beginning to occur and this was noticeable in women who had trained and worked as Traveller Community Health Workers.

'…But a lot of women since we started on the courses and that are starting to change – they are starting to look after theirselves more than the younger ones and kind of letting the younger ones do what they have to do theirselves, you know what I mean, they are encourage them and tell them what's out there and tell them, give them plenty of information and encouragement and those things' (Older Women).

'…all the women that's on the sites that are not doing the courses, you know what I mean, and didn't have the information that we had, they weren't just, they weren't really bothered about theirselves but they're more looking after the family, worrying about the family and the husband and they weren't caring about theirselves. You know what I mean, we tried to change that woman' (Older Women).

Trust

As discussed throughout the report, other important factors include lack of meaningful exposure and communication (cross-cutting ties) with settled people, a general mood of negative regard toward Travellers, distrust between Travellers and non-Travellers and distrust by some Travellers of other Travellers. Greenan (2009:57) also points to issues of trust. Trust is considered an important component in health matters and the expanding literature on this currently reflects the importance of the relationship between trust and health. (See Alaszewski, 2003; Mechanic, 1996; Barrett et al., 2007). Trust is earned and is about the 'body language' of an organisation as well as the overt message. As Wynne has pointed out, there is always more being communicated than what the communicator thinks s/he is communicating. It is based upon a general assessment of the institution, past record and multiple factors and is always fragile (Turner, 1996; Turner and Wynne, 1992).

The data suggested that many women felt that Traveller problems and issues were beginning to be heard and listened to, at least by some. Trust emerged from the focus groups as a major issue. Traveller women thought that outreach services facilitated Traveller trust. This was reported to enhance the uptake and use of services such as screening as borne out in ROI census data when Traveller healthcare workers were able to mediate between the services and individual Travellers in the community.

'…But I know the older women in X there's some of them that never had a smear test done in their lives and we have these women going around the sites doing the outreach and eh they explain to them how serious it is and eh to have them done and even the younger women as well never heard of smear tests. And the breast exam, it was the same with that – mammogram. Now thank God when they are going and doing their own thing, and making their own appointments and keeping their appointments, a lot has changed' (Older Women).

For those women who had the opportunity to train as Traveller healthcare workers, this has also afforded contact, support, trust, knowledge, payment, structure, social separation (from spouse, family and home), and promoted self-esteem and confidence. However one woman raised the issue of ambivalence, which was greeted by a consensus of opinion. She explained that with the discovery of new knowledge, and experiences women appeared to have a more positive outlook. Still, the new knowledge had also made women more aware of their disadvantage as they compared what they have to the broader community and realised what their younger families were missing out.

'…Yes, before we started in the Primary Healthcare that you understand what rights is mostly now, but there's a lot of Travellers that doesn't – you will be left sitting in the queue and then there's people brought in before – you were only there beforehand' (Women).

Civic Engagement – Men's Experiences

Many Traveller men talked of loss. This includes loss of structure and meaning to their lives. They reported hanging around, searching for a means to earn extra money, or trying to find things to do to relieve boredom.

'…When the money runs out you go home' (Men 2).

This mirrors accounts reported by van Cleemput and Parry (2001), Repper and Perkins (2003) and Parry et al. (2004).

They were concerned with the need and loss of passing on traditional values and skills and were worried that the jobs were not there for younger men. Some Travellers said that they had built up a good reputation as builders, painters and handymen and were able to get their sons into the business. But for many men losing the ability to pass on traditional skills to their sons was regarded as a personal loss as well as a communal one. The data indicated that men felt a loss of tradition, role, self-esteem and structure, (economic, social and personal structure).

They also reported having degraded (formerly multiplex, now increasingly uniplex) relationships, once regarded crucial as a source of economic, social and information exchange, help and social capital, (limited that it might be). Horses remain culturally significant to many Travellers. Meeting other Travellers at markets, fairs, farms, roadsides, or camp/bonfires on commons or wasteland also had

manifest (social and economic) functions as well as latent (social health and psychological wellbeing) functions. In addition to economic exchange these meetings acted as social and ethnic bonds, marriage markets, increased sociability, leisure and fun, serving a function of reinforcing friendship and identity.

Bourdieu (1984) defines social capital as referring to valued social networks. Social capital may be measured in terms of the quantity and quality of social, economic and psychological support from family and kinship networks to help individuals and families overcome difficult situations or life events. However the degree of human agency and choice inferred by this was particularly limited for Travellers as the quantity of these contacts appear to have diminished and the quality in terms of social and economic value appeared to be low. Also positive social capital gain or advantage appears to be offset by negative social capital effects such as negative interaction and peer pressure leading to risky behaviour. One example of this is in sharing medication between family members, for instance. Also death experiences were closer to Travellers, with Travellers dying at a younger age. This meant that a tragedy such as a natural or violent death appeared to be a more shared experience by the wider Traveller community. Traveller men, women and young people expressed concern about suicide clusters[27] . Bourdieu (1999) demonstrates how individuals or groups may internalise negative views of themselves and of their group, such as feelings of powerlessness and worthlessness and considers this as 'symbolic violence'. Greenan (2009:7) also noted that social capital did not necessarily produce positive outcomes among Irish Travellers.

Cross-cutting ties with settled people, while important for everyday living were often considered as being on a different basis of trust, since stereotyping and perceived racism were regarded by Travellers to be constantly in the background. That is not to say that some of these ties were not important or enduring. The data revealed that where Traveller men came into meaningful and prolonged social or leisure contact (e.g., playing football) with men from the settled community, this helped establish a degree of trust and friendliness. Traveller men interpreted this as important and enjoyable.

Traveller men were highly pessimistic and fatalistic in outlook. Many men also agreed that they only felt truly comfortable around other Travellers.

'*…Yes you are a bit paranoid, you are looking around to see did anyone notice that you're being a bit paranoid and stuff like that and, and people don't realise that the stress that that bring on a person. Sometimes the Travelling man has to be macho, he goes outside and says 'Ah f*** it' he laughs it off and stuff like that*' (Men2).

Feelings of personal discomfort were often heightened when Travellers faced authoritative figures and agencies.

[27] Several suicides occurred during the study period.

The macho orientation among some Traveller men was said to be promoted from a 'toughen up' socialisation process designed to make young men resilient in the face of extreme adversity, i.e. in the form of conflict with non-Travellers and other Travellers (Women Generic 2). This process was also discernable in the data analysis of young Travellers, especially the boys. Young Traveller boys and to some extent girls talked of bullying at school when the only way to survive was reported to behave in a tough manner towards the instigator of the bullying. When asked by the researcher if there was any other solution, several replied that it was better to be scared of then scared, but they mostly wanted it to stop as a matter of priority for them in both groups across the genders. (Young people, Rural and Urban).

Gender culture has the potential to feed into forms of self-destructive behaviour such as health and medical avoidance and/or risky behaviour[28]. This also holds for the general population but is particularly potent among Travellers.

Traveller men also talked about involvement in acts of bravado that might be usefully described as 'Bantam Cock' Syndrome.

'…Say it straight out men, we have as many problems with the mental and physical health as women have. It is for the sake of bravado and the chest out like a bantam cock we won't talk about it, because men should talk about it. But the bottom line is our problems are there' (Men2).

There is some evidence to suggest that these attitudes and behaviours have been cynically exploited by Travellers and non-Travellers. Men reported that Travellers traditionally typically fought controlled duel fights over particular issues, usually until first blood. Because they were often between kin they were usually held away from wider family. Many of these are now said to be proxy fights. Some of these have escalated into feuds and on occasion riots. Men and boys are often unaware of the dangers of this type of risk taking behaviour.

The bases of social (gender) role separation from the household was also said to be undergoing change. Women reported that some men have begun to take on childcare roles particularly when women are out working or at training centres.

Paradoxically, despite men and women reporting that men have more freedom, control and autonomy, men do less well compared to women as triangulated throughout the report. The data suggests that men internalise health issues and private concerns. Similar alienation is recognised to be experienced by non-Traveller men in other contexts, particularly among the lower socio-economic groups and ethnic minorities, the unemployed and retired. In recognition of the need to address men's isolation, communication and health needs, the 'Men's Shed' movement in Australia is currently expanding to address men's social and health issues (Golding et al., 2007)[29] . The literature on Men's Sheds could

[28] Gender culture also influences perceptions of body image, body regulation and behaviour (see for example, Courteney, 2000; Monaghan 2001).

usefully be translated with appropriate consultation with Traveller men and adapted to suit their needs, , for example, a caravan where they can meet and work on practical hands on skilled work of their choice. This needs a proactive role from the Service Provider:

'…from the research that we have done (local yet unpublished work on men's health) with Traveller men, there is a hunger for that engagement, they want that opportunity' (SSI: Service Provider).

Recreation

Gender and age appeared to be significant factors here in terms of recreational opportunities. Boys and men experience different opportunities and barriers than girls and women. Being a female Traveller means that opportunities are more restricted. Young boys were afforded more freedom than young girls. This appeared to be largely influenced by the traditional division of labour, with girls expected to be located more in the private, domestic sphere than boys and mirrored adult power role differentials.

Boys reported that they enjoyed boxing, football, some liked horses, helping at markets and going into town. The girls tended to be more home-focused, enjoying going to town when allowed and appeared not to use youth clubs as much as the boys because of parental objections on grounds of safety and the perceived need for modesty.

Travellers' experiences of being unemployed meant that their time was more loosely structured. Finding things to do was important. Men said they were interested in a range of sporting and leisure activities, including, horses, traditional road bowls, boxing, walking, football, fishing, drinking, socialising. Also reported were, golf, gambling, horse racing and 'the bookies'. Younger men were said to have more opportunities than older married men. Older men reported that younger men drink more alcohol, while a GP reported that younger men appear to,

'…Have tremendous difficulties with self-image – due to anxiety' (SSI: Service Provider).

This has been confirmed in the literature when discrimination and racism are internalised and young men are more likely to engage in risky behaviours (Thompson, 1999 in Mind, 2010)

'…Traveller men said they get dangerous amount of freedom after they leave school, which is different from the lack of freedom given to young women. There's a huge inequality of treatment there… and for young men that leads to high risk behavior and that's going without any checks or balances and because these lads are not linking in with anybody, they are completely disengaged. They are disengaged from national school or secondary school at 14-15 and nobody sees them again, ever' (SSI: Service Provider).

[29] The shed movement typically identifies the importance of men's space, via sheds and workshop tasks. This provides for men who have proved difficult to engage through conventional health employment education and training initiatives. These are specifically designed to assist men who are experiencing problems with significant change, health, social isolation, unemployment, positive self image and a range of other issues. They provide 'mateship' sense of belonging. This can provide hands on practical learning.

In contrast, women tended to socialise with other family members in the private sphere and focused on immediate family needs. There appeared to be little opportunity for socialising beyond the immediate local context.

Secularisation

For many Travellers the (Catholic) Church remains important, although an increasing lack of respect was noted because of recent Church scandals in Ireland. With the absence of political structures or organisation beyond the family, the Church, and priests in particular, have historically occupied an important role for Travellers. This was the one authority that Travellers would have traditionally respected and a major source of information and ideology/or world view. Many Travellers however perceived religious belief as not being as important as in the past. The uptake and use of contraception particularly by women might be taken as a marker of this, for example.

'…*Things have changed a lot, the way they use the service, contraception and stigma and asking for smears used to be secret and hidden but now is more open*' (GP).

Women and Violence

The United Nations defines violence against women as;

'any act of gender-based violence that results in, or is likely to result in, physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life' (United Nations 1996).

The World Health Organisation states that violence against women is a major public health problem and a violation of human rights. The Women's Health Council published a number of reports on women and domestic violence, the most recent of which concerned a study of gender-based violence and minority ethnic women in Ireland (Women's Health Council, 2009). The study comprised a literature review of international best practice, a quantitative assessment of the scale of gender-based violence and a consultative process with women of different ethnic backgrounds, including Travellers. The report adopted an ecological framework at 4 levels, from wider society through community, family/ relationships and the personal history of the abuser. A comprehensive set of recommendations was made. In Northern Ireland the issue is also appreciable. For instance, according to Women's Aid NI 29% of murders in Northern Ireland involved domestic situations (Police Statistics, Women's Aid NI, 2010).

Domestic violence is evidently of general concern to all communities both globally and when considered historically. In that sense it is not a new Traveller issue but a gender issue. Concern specific to the Traveller community was addressed by Traveller representatives. Pavee Point (one of the Irish Traveller organisations based in Dublin) for example, argues for the right of women to self-determination and ownership of their bodily integrity and the respect of Traveller culture. They demand human rights for Traveller women and children that include a right to safety and a life free of violence, within the family, the community and the State.

The reasons connected with the cause of violence and the inadequate services documented in the literature on domestic violence generally form the background for any discussion in relation to Travellers' experience of domestic violence (see for example the Women's Health Council 2009 report). However, the focus group and semi structured interview data suggest that belonging to the Traveller community requires specific consideration when discussing and offering services to women and children.

'While the situation for all women who have to leave their home in search of a violence-free life is difficult, Traveller women experience additional dilemmas that make it more difficult for them to access help and support and explore their options. This is brought about by a combination of discrimination in services and professions (institutional and individual) and a lack of culturally appropriate provision' (Traveller Health, A National Strategy, 2002-2005).

Similar points are made in respect to Travellers, both in ROI (WHC, 2009) and in the UK (Greenwich Council, 2005).

In addition, several Traveller advocates raised the issue as being of serious concern. It tended not to arise spontaneously in many focus groups, and there was no topic specific focus group held on the issue but did come up in different groups on several occasions and appears to be a largely taboo subject, involving pride, shame and stigma. Within a focus group context where close community with inter-family ties existed with consequent anonymity difficulties open discussions were discouraged in this subject instance.

The issues arising from the data from both Travellers and Traveller advocates include perceptions of a system whereby some safe hostels are thought to operate. It was reported that in some cases only a few Traveller families are allowed access to the shelter at any one time. In addition, the number of children the women are able to take into the hostel and some having some older male children may make it more difficult to gain access to help because of practical considerations and facility size.

'…There are barriers to access. Why don't some women use the services on offer? For example, if a rule says no men but a woman has a teenage son then she may not be able to use the place' (SSI, conducted in the scoping stage of the research).

Making a decision to seek help for any woman (accepting that men may also need to seek assistance in some instances) is acknowledged as a key step in any case of domestic violence but the data suggests that it is a more difficult decision for Traveller women facing abuse. This is partly because of the nature of marriage bonds and family kin networks when interrelationships are very closely tied in the community. In this case, leaving a husband also means leaving a whole family network and risks a consequent exclusion from the family/community network and isolation.

The patriarchal community culture and male power over women was reported by one Service Provider as resulting in a situation,

'…where a woman was attacked by the husband's friends for leaving or attempting to leave the husband' (SSI: Service Provider).

Much of the feminist literature would support the view that male violence is a manifestation of the desire of men to exert power over women. Intervention strategies suggest an approach that teaches men how to control anger and improve interpersonal relationships by expressing feelings and removing frustrations and anger (Hanmer and Itzin, 2000).

Many women reported, 'putting up with it' since it was difficult to obtain help from outside the community and when discrimination impacted on the likelihood of being listened to. For many women, there is an economic imperative as well as a social one to try and cope at home. The perception is that there is little choice as there is nowhere else to go.

The data here evidences several Service Providers who noted the existence of violence against women by men when it was reported to be very severe in some cases.

'…I have seen women with very serious injuries' (SSI: Service Provider).

Still, some women did report that it had become normalised in the community, that is, it had existed through generations, a *'just get on with - it I had to'* attitude.

Traveller advocates stressed that *'…Traveller men are not inherently violent'* (SSI: Service Provider).

Education and opportunities for women and girls to improve their self-esteem and confidence were seen as necessary to break the cycle. Education of men and boys regarding the need for equality and conflict resolution skills were also discussed. Early years support for families with complex needs from birth was advocated by several service providers to adequately support child witnesses of abuse (SSI: Service Providers).

'…The violence at home that some very young children have witnessed can clearly be seen played out when observing children at play' (SSI: Service Provider).

Some factors relating to the use of services relate to a reported lack of using help lines, women do not always have access to a mobile phone or control over them because of power differentials or in some cases the privacy to make a call, nor do they have information about whom to contact. Literacy problems and a lack of exposure to wider social networks via adequate education and social networking or access to a laptop or PC exacerbate this in some instances. Research in Tullamore reported that women were more likely to seek assistance from a priest as there is lack of knowledge about available services (Duggan-Jackson, 2000).

As discussed elsewhere, trust in Service Providers is crucial if women are to feel safe enough to confide problems and fear is to be removed. For example, one Traveller advocate remarked that

'…A & E services are said to need to offer privacy when offering accounts of the reason they are attending for treatment' (SSI: Service Provider).

This reflects the wider need for education and training of service providers to inform, enable access to and offer culturally appropriate services to women and children affected by domestic violence. The use of services could be monitored via an ethnic identifier in ROI as determining usage of services in this area is otherwise problematic.

Sexual Orientation

'Sexuality' or 'sexual orientation' describes the combination of emotional, romantic, affectionate and sexual attraction towards another person. Lesbians and gay men experience this attraction towards members of their own sex; bisexuals experience this attraction towards members of both sexes. The initials 'LGB' have begun to be used by Service Providers and Government policy makers to refer collectively to people who are lesbian, gay or bi-sexual (Stonewall, 2010).

The literature suggests that being LBG in any community is experienced differently according to the existing culture in that community and the surrounding society. It is also said to depend upon gender, age, and any disability present and ethnicity or minority group status. The Travelling community data supported this in various ways. One key respondent reported that it is not simply a matter of ROI or NI differences. The data suggest that it is significantly influenced by both gender, family values and the immediate culture experienced by Travellers, which includes discrimination. For example, the degree to which gay Travellers were accepted in the past within a given community was said to be relevant. Accounts offered at interview ranged from where there had always been examples of gay male couples who were known and largely accepted in the community, to cases where homosexuality was denied and had to be hidden.

'…Some families are more liberal than others depending upon how traditional or liberal a particular family is' (SSI: Service Provider).

As noted elsewhere in the data, Traveller culture is characterised by being a patriarchal culture. It seems that because of these entrenched traditional male and female roles, it may be easier in some cases to be a male involved in a same sex relationship than a woman. This appears to be related to the amount of power men have compared to women. They are able to go out more and range further afield, and so be more anonymous and experimental outside of the Traveller community but still be accepted within it.

In order for gay men to fit into the community, for example,
'…A man might get married and then leave or divorce his partner but would have escaped the bachelor image and be accepted as 'straight' and be able to retain his position in the community' (SSI: Service Provider).

However, it was reported to be at least as difficult and perhaps more so for women as one respondent noted.

'…It's different for women, Traveller girls and women don't talk about sex, sex talk is still taboo and so is sex before marriage, so female gay sex as a mindset isn't possible, there are a whole lot of issues there' (SSI: Service Provider).

There are reported similarities to being LGB in both the Traveller and the settled community, that is, there is a stigma attached to it referred to as homophobia for many people some of the time and it is therefore difficult to broach the subject. There is a reported wish not to disappoint the family for not being a heterosexual male.

'…There is an expectation that men will procreate and carry on the family name. An awful lot of Travellers are hiding the fact' (SSI: Service Provider).

'…I knew from being 15 years old but it took me 8 years to quietly come out to my family. It turned out to be OK. I had no problems and was very lucky' (SSI: Service Provider).

But it was noted that it is not always an easy option,

'…I know a couple of gay people who had arranged marriages planned and who had to change their names to protect themselves and their family and went to live with the settled community' (SSI: Service Provider).

Being a gay Traveller was reported to risk double jeopardy sometimes as it was both difficult to come out as gay in the Traveller community and difficult to declare a Traveller identity in the gay community. Being a lesbian might be considered a triple jeopardy.

'…So you can be between a rock and hard place' (SSI: Service Provider).

In reference to being LGB and belonging to a minority culture Mind (2010) reports that *'having to choose between their sexuality and their cultural identity, they may fear exclusion from the support networks of their friends, family and culturally specific organisations if they 'come out''.*

The literature indicates that drug dependency, alcohol consumption rates, depression, anxiety and mental ill-health are affected by homophobia and internalised homophobia. This had consequences for mental health and suicide. Bullying in schools was a further factor and self-harm and eating disorders were an additional concern for lesbians and bisexual women (Warner, 2004; King, 2003; Hunt and Fish, 2008 in Mind, 2010).

A further example told of women who had married young, had children and then 'came out' as lesbian. It appeared to be more difficult for women, but again counter examples were offered of strong women who had been openly gay. This is not at odds with the general population but the more entrenched

traditional/patriarchal gender roles in the Traveller culture perhaps deepen the impact of being gay. The opportunities to form a new life and identity are more constrained because of the close family ties and intermarriages which create more interlinked relationships and exclusion from broader influences and opportunities.

This issue is fed by a lack of opportunity in education and employment and general negative socio-economic determinants. Leaving a spouse or fiancé also means family exclusion to a large degree so there are more social, emotional and financial risks to consider.

Sexual Health and Information on Sexuality

There was a reported lack of much needed culturally relevant information for both 'straight' and LGB Travellers in the area of sexual health and sexual orientation generally.

'*…But it is still a touchy subject*' (SSI: Service Provider).

Any attempts to increase knowledge in the Traveller community around sexual health and sexuality was said to need to be done thoughtfully. The best approach was thought to be via consultation with Traveller support groups, Gay Traveller support groups and organisations were also reported to be another source where culturally appropriate literature might be disseminated.

Again, this is reflected in positive actions from a range of existing support groups in the United Kingdom such as Stonewall and MIND. Another Traveller advocate noted a 'cultural lag' because of the history of exclusion from education and wider society. Many Travellers were not aware of many of the issues that had been debated in society on homosexuality. The Catholic Church had been a leading influence in the past.

'*…Gay women, lesbians are invisible because of gender roles in the Traveller community. It is unthinkable, but gay men have freedom Traveller women don't have, they can manage to explore sexual orientation. Women are watched and have no freedom. Why do we equate sexual orientation with suicide- because as a community we are not aware of globalisation, secularisation, there is an educational lag – people are now watching Eastenders with a gay storyline – it's information*' (SSI: Service Provider).

Homosexuality as a subject was therefore said to be still undeveloped in the community where it remained relatively undiscussed. It was suggested that the gap might be bridged via the Traveller Community Health Workers in future.

This section merely touches upon what remains to be a largely taboo subject within the Traveller community but one where there is scope for sensitive consultation on the needs of young and older LGB Travellers via Traveller organisations.

Addiction and Drugs

The health-related lifestyle issues of concern to Travellers were addiction, alcohol and drugs, rather than diet, physical activity and smoking.

Addiction and drug use was interpreted as mirroring the experiences of the general population and not something solely related to Travellers. While addictions straddle the social class spectrum, and may be seen as a general societal problem, the lower social classes and marginalised groups appear to be disproportionately affected because of the influences and stresses imposed by their relative socio-economic position (see Wilkinson, 2005; Haustein, 2006). The detrimental effects of low wages and unemployment are well recognised. Research into mass unemployment in the early part of this century, and again in the early 1990s in Britain for example found that unemployment increased the chance of being ill and rates of depression, particularly in the young[30] (see also Marmot and Wilkinson, 2001).

Separate concerns were raised about the use of alcohol, illegal drugs, legal drugs and medication. Iterative feedback suggested that addiction and drug use were significant and an ongoing concern in Irish society but this appeared to be more problematic in ROI[31] .

'…Alcohol and drug use which has increased…there is a greater pressure on services' (SSI: Service Provider).

Travellers interviewed in NI reported that hard drugs were not a major problem in NI compared to the UK and ROI although respondents knew of pockets in one or two small towns in NI[32] . This was confirmed by a Service Provider in NI who reported an increasing drug problem in the Traveller population in line with the settled population following the 'Good Friday Agreement' in Northern Ireland.

'…The pattern of medication has changed. Benz's and analgesics are requested much more now. Illicit drug use and addiction has changed along with changes in the general population since the ceasefire. It's not like X, no heroin use, but increasing use of cocaine, ecstasy and dope have increased' (SSI: Service Provider).

It was understood that there had been a 'drug scene' in ROI for a considerable period and Travellers appeared to have a conceptual schema in relation to addiction. This ranged from habitual alcohol abuse through to hard habitual drug abuse and poly-substance abuse. In several focus groups Travellers stated that use of hard drugs such as cocaine has increased in ROI (see also National Advisory Committee Dn Drugs, 2008).

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[30] See for example, Hurlburt (1932), Morris et al. (1994), Mathers and Schofield (1998), Bartley et al. (2004), Morrell et al. (1998).

[31] NACD facilitated 20 focus groups with 137 Travellers, of which 12 were in Dublin, 2 were in prison and one was with Traveller community leaders. They also conducted a further three focus groups with agency workers and one to one interviews with 15 Travellers who were drug users and 26 agency workers.

[32] Paramilitary organisations had for decades exerted control of drugs and drugdealing in NI. See for example, 22nd Report of the Independent Monitoring Commission, 4 November 2009.

There was thematic prevalence on issues surrounding drug and alcohol availability, abuse and addiction. These emerged spontaneously from different qualitative data sources and from discussions with many Travellers in different contexts.

'…The way I would look at it from a Traveller's point of view is when the drugs culture hit Ireland, I would say in the late sixties, even seventies, it was the settled community that is the parents who were in denial because this just came in and it just went through the country, particularly in Dublin, it started in Dublin' (Addiction1).

Alcohol

Alcohol was viewed as socially acceptable and was seen as an important social outlet for men. It was not seen as a drug and was not necessarily regarded as dangerous. Men tended to downplay problems of alcoholism (Addiction2).

'…Traveller women don't go to pubs but off licenses to get drink. Men go out with men, but women stay on the site with children. The women hide it' (Addiction1).

The age structure of Travellers along with lack of alternative role models in their community also makes them vulnerable to risky and self-destructive behaviour. 15-35 year olds represent a sizable proportion of this population. Traveller truncated lifespan essentially requires that children grow up and experience adult life more quickly than children from settled communities. The role models (adult responsibility, drinking, driving, getting married, child rearing, combative prowess) for behaviours throughout the lifespan are younger and adult events happen earlier.

Many Travellers were concerned that alcohol be included in the category of addiction. There was concern about a hierarchical sequence of drug abuse often beginning with alcohol and progressing to mild then hard drug use. Alcohol addiction was also flagged in relation to Travellers in prison.

'…Travellers would feature as a significant group within the AA' (Addiction1).

There was general concern about what was described as a trajectory of addiction. This demonstrated the connection to actual and perceived exclusion of Travellers from public houses and other licensed premises. Exclusion from bars and hotels was a major issue. Travellers thought that discrimination and social stigmatisation leads to isolation forcing them into hidden and unregulated drinking, and to exposure to harder alcohol and soft and hard drugs and antisocial behaviour, criminality with further stereotyping, labelling and victimisation. The centrality of perceived discrimination illustrates how this impacts on health behaviour. The following narrative is illustrative of this:

'…It's back to discrimination It is easier for Travellers to get drunk than it is to go to the pictures or a disco or to a local pub or anything like that. So I think they are very much isolated' (Addiction1).

'…If a group of Travellers want to go out for a night out, do you know what I mean like, the chances are they are not going to get served locally – because they say that – even with local guys – so where do they end up? They end up in some alley or some field and when they are consuming alcohol, and again it is not just a Traveller thing when you are consuming alcohol, it leads to the next thing' (Addiction1).

The narrative became a familiar one, discussing a trajectory beginning with alcohol experimentation. This pattern is well documented in classic social science literature (Young, 1971; Mayock, 2002). This indicates stages and pathways of drug involvement, the so-called Gateway Hypothesis (Kandel, 2002). This has been supported by Fountain (2006).

However, there was also concern that Travellers don't necessarily follow this pattern but that some go directly to hard drugs.

'…Some go straight to cocaine. The worrying part is that there is actually no progression…and there would be middle-aged men who would have drank of course but wouldn't have tried tabs or hash and went straight to cocaine at 45 years of age' (Addiction1).

This illustrates that the Gateway Hypothesis although relevant to Travellers is only part of the story. Rather causation is more likely to be a result of extreme social and living conditions experienced by Travellers. Also expressed was the fear of a pathological genetically inherited disposition:

'…The years in my 20s and even now I live in fear that I am genetically programmed to have a drink' (Addiction2).

One Traveller said that many don't understand the symptoms of alcoholism:

'…They think they are only having a few drinks' (Men 2).

Illegal Drugs

There was thematic prevalence in the data in relation to concern about illegal drug use within the Travelling community. Some Travellers were careful to emphasise that addiction and drug abuse was not a Traveller only issue but emphasised that the problem was *'…serious'* and *'…widespread'* (Men2).

'…Drug addiction is in all societies' (Addiction2).

Travellers perceived drug issues among Travellers as being externally *'invisible'* by the general population, but is clearly obvious within the Traveller community.

'…Drugs is a huge issue, more so than people lets on about – cause they've [Travellers] no community' (Addiction1).

'…It's mirroring what is happening in the settled communities starting to happen in our community well, but [on ac]count of our community being so small, it is easy to see it' (Men2).

The narrative illustrates how Travellers are more vulnerable because of their reduced material circumstances and low self-worth, because their close-knit community and traditions prevented them from taking things outside the family/community and because of a sense of embarrassment and shame. Discriminatory practices and social exclusion uniquely add to this vulnerability and were recounted in narratives of Travellers.

'If you experience racism, if you are relegated to a thing rather than a person and you find yourself with no work and you are completely excluded, marginalised from society, I think that has an effect' (Addiction1).

In 2 focus groups with Travellers, the perception among participants was that access to drugs was easier in prisons and that prison life exposed many Travellers to drug use and hard drug use. Several Traveller men in ROI also said that they experienced drugs and particularly hard drugs for the first time in prison.

'…I think it depends on where people start, I think you know some drugs it started out in the local area whether its cocaine or hashish or E, whereas other drugs...like heroin…when you look at it a lot of people come into contact with heroin when they are in prison…so it depends on where they come into contact with them drugs because more than likely they wouldn't come into contact with heroin' (Addiction1).

Travellers are particularly vulnerable to peer-pressure and the narrative showed that drugs were becoming more open, public and acceptable 'normalised', and came to be expected at key social events such as weddings. This 'normalisation' of substance abuse has also been described by van Hout and Connor (2008).

'…It is so normalised now that if you are offered it (referring to drugs) and you refuse it YOU are the abnormal one. Now that's my own limited experience of that particular thing' (Addictions1).

'…There's even a lot of women on drugs now – sure that was unheard of. I know an awful lot of women on drugs – hash, and cocaine and heroin and things like that' (Addiction1).

'…She was just coming home from school and the bus drops her off on top of the hill. My sister was over walking and she seen this powder stuff, but it was in a plastic bag with a zip on. It looked like sherbet or sweets or something like that. She brought that down to my dad and my dad looked at it and it was drugs, it was cocaine' (Young People2).

Yet drug addicts were heavily stigmatised and shunned within the Traveller community. Service provision was perceived to be weak and often inappropriate in this area. It was understood by Travellers that there was a lack of available treatment options for drug addicts, including access to clinics and centres. Where treatment is available services were perceived to have long waiting lists. An additional

perceived barrier was in terms of requirements for treatment (i.e. that person had to be clean for a week before being admitted). These were deemed problematic, because of high peer pressure low levels of support, lifestyle and social/environmental factors. This meant that many addicts become isolated and extremely vulnerable and were often forced out away from their family/community with virtually nowhere to go often ending up with other drug users in even more vulnerable circumstances.

'…I mean if you take cocaine yeah, you take heroin and there's a lot of heroin use, a lot of younger people's on heroin. The Travellers on heroin gravitate towards the city 'cos they are kind of ostracised as X was saying, and then they group – you see that – I know a good deal of them around town you know and its as if a lot of them younger women and men. They are both either smoking heroin or injecting it and its actually getting bigger you know' (Addiction1).

'…Heroin users are very vulnerable, younger Travellers men and women. Like I see them every day of the week. Some of them I even know from when they were children and you know it is really terrible to see them and the deterioration' (Addiction1).

The case study on drugs from a former addict confirms the focus group narrative suggesting that Travellers perceive that there are not enough services to deal with addictions. Inter-agency communication was reported to be slow and this was perceived to have a knock-on effect on health (given the urgency of addiction). The case study also reported that the situation was worse for addicts in the winter since many were homeless and had nowhere to go (Case D).

Data from multiple sources also discussed abuses of alcohol and drugs and how this also affected behaviour such a sexual promiscuity. It was also reported that fights and feuds sometimes occurred because of extramarital affairs.

The data also pointed to links with antisocial behaviour, community conflict, financial exploitation, suicide, para-suicide (this was attributed to not being able to repay money owed for 'gear').

Denial, avoidance and shame

Addiction and drug abuse in the Traveller community is largely unspoken and hidden. Travellers reported that while they knew of drug use in the family and community this was largely ignored. They were reluctant to go outside the community for help because family/community norms precluded that they seek help from outside. Men also said that Traveller independence as well as discrimination, victimisation and lack of trust of the police and other services were part of the problem. The narrative stated that men and women also felt ashamed to seek out information and advice.

'…Travellers know about extent of the problem but deny it. It's a shameful thing' (Addiction2).

'…There is denial, but I wouldn't confuse that with not knowing. There is a difference - I think actually. I am strongly of the opinion that the vast majority of Travellers, parents, sons, daughters, brothers and sisters know exactly what it is. But they will deny it. So let's distinguish between denial and not knowing – they do, but they

will deny it – they know what's going on. M3: yeah, exactly and I think you touched on it and they keep using the word denial, but I think they know, they do know, that's a shameful thing you see. Instead they bring them down to the cure man or something like that or holy man' (Addiction2).

'There is a lot of denial among the Travellers, even if they know a member of the family is using drugs. It's hidden you know, they see everyone else but they don't see their own' (Addiction2).

'…We have Travellers; young Travellers that are overdosing themselves...their parents are still denying that they have a drug problem. Now I'm saying that – we've just lost, I just lost a family member – I was the first I would say to admit and on the day I was asked by the parish priest do you want to say how he died and I said yes. I am the eldest of my family of X and I said I want the people who came here today to show respect to know how he died – I wasn't ashamed, but a lot of Travellers are still ashamed' (Addiction1).

'…Quite recently we had another Traveller that overdosed himself – it was well known by other Travellers that he was on drugs but yet the father and mother; even weeks afterwards said he was never on drugs. So how can ye counter that' (Addiction1).

The data suggested that Travellers perceived they had limited access to information on addiction and drugs and individuals did not fully understand the potential personal and social consequences of alcohol or substance abuse[33]. The narrative supports other evidence showing Travellers to be at high risk of developing problematic drug use due to their social exclusion from common leisure, social and recreational outlets (The National Advisory Committee on Drugs, 2006; Pavee Whiden, 2009).

Men also considered the interconnectedness of multiple and different influences on health chances of Travellers.

'…It's widespread within the Travelling community because our young people cannot get employment right, therefore they have more time on their hands Like, you look at poorer areas there are the ones that usually has high unemployment and you know, drug problems. And therefore you are going back to them where the Travellers are. Where, we have high unemployment. We have all the highs of all the things. We have it as a community not as an area' (Men2).

'…They run to a cure man or run to a priest. That's the big religion in the Travelling community, that's their tradition but what they don't understand is when they have a family member that's an addict, its what do you do about that' (Addiction2).

Drug abuse in particular, was perceived as a major health threat to men in the future. Men expressed helplessness in the face of increasing illicit drug use. There was consensus that the problem was getting worse.

[33] In response to this Travellers themselves have produced video commentary designed for Travellers to warn about drug and alcohol abuse within the community (Pavee Whiden, 2009).

'…Addiction - I think that is going to have a major impact on Travellers in the next couple of years' (Men1). Many Travellers said that they thought the problem was beyond the scope and control of the individuals, the family and the Travelling community and were concerned that it was even beyond the scope of Government and healthcare agencies.

Prescribed Medication and Iatrogenic Addiction

Traveller women reported high levels of stress. '*Traveller women as Travellers are kept down their whole lifetime'* (Addiction1).

There was also thematic consistency on the issue of prescribed medication. Several focus groups and interviews in ROI and NI also reported concern in relation to prescribed medication particularly among women:

'…There is a lot of prescription drugs' (Addiction1).

Depression was generally regarded by men as a women's disease but there were indications that this was changing. Women thought that depression was never properly assessed and counselling was usually never offered. Overmedication was said by many women to be a major concern. Men and women said that prescription sleeping tablets were not monitored. Some focus groups reported that some doctors advocated repeat medication, particularly for women. Travellers reported that they often did not see the GP but were prescribed drugs on the basis of earlier assessments. The narrative also discussed how other GPs were reported to be surprised at routine over-prescription by some GPs. There was also concern that this medication was, 'getting into the wrong hands'. Young children sometimes collect prescriptions. Older Travellers often relied on children to read medication and dosage.

Women were worried about overmedication and addiction and voiced concern about the overreliance of prescription medication and that this was not recognised as drug misuse. The overprescription of tranquilisers to women is also documented elsewhere (see Gabe and Calnan, 1989). The data showed thematic prevalence of prescription drugs as a major concern for Travellers, particularly women (Addiction2).

'…They just give out the boxes. My sister was prescribed Valium and I took them away. We went traveling last year and she was doped out of her head on them and to me a doctor like that should be struck off. A proper doctor would only give you a small supply. No one bats an eyelid at what they do' (Addiction2).

Exchanging and in some cases the selling of prescribed medication (antidepressants and sleepers said to be sold for 5 Euros a bag) was also reported. There was also consensus that there was absolutely no recognition or support for those addicted to prescription drugs.

Men and women both talked about self-medication. It was usual to take a painkiller before seeing the dentist for example. Women reported that they shared medication, a man frequently taking his wife's medication, but reported that they did not share medication when it came to medicating children.

The data also suggested that once symptoms began to ease Travellers tended not to finish the course – antibiotics, for example. This was particularly the case if they didn't have a medical card. Although it was reported that with information being passed down from Traveller health workers regarding the need to take a complete course of antibiotics and that this was beginning to filter along the information chain.

Travellers regarded themselves as being particularly vulnerable because of the lack of information and understanding of the health consequences of drug use and also because of their reduced social and economic circumstances and they perceived that services are inadequate or 'services are not visible' (van Hout, 2009).

'…There is no real appropriate treatment there for Travellers. I mean you look at the history of St Vincent's the alcoholism among Travellers and look at the uptake of AA services. Little uptake of services. So the services are not there for Travellers' (Addiction1).

One Service Provider noted what he perceived to be:
'…an underdiagnosis of severe depression and psychosis amongst Travellers. Many providers who do not work regularly with Travellers do not know what the norm represents or understands their culture in the same way they do the settled population….The provision of mental health was patchy depending upon region. Where you live makes a difference' (SSI: Service Provider).

Also one focus group reported that in spite of financing, reports and recommendations, services are inadequate for the specific needs of Travellers.

'…How can a settled person understand the pressures a Traveller is under' (Addiction1).

'…It's like me going to a counsellor and knows nothing about being a Traveller. How would that person understand why I am depressed' (Addiction1).

For many, the services might as well not exist because Travellers don't know about them. Services are perceived by Travellers to be not dedicated to their specific needs (see NSE Report, 2006).

The findings point to a need for culturally appropriate services. In response the HSE funded and supported a range of Traveller Primary Health Care Projects. This model has been regarded as a success by Travellers who fear that the momentum and gains afforded by these projects will be lost if continued funding is not secured. This has also sponsored a direct dialogue between Travellers and the HSE and has begun to build trust.

The nomadic lifestyle does not easily fit with easy use of existing services. It was perceived that the operating guidelines for some services appear to exclude Travellers. Mental health services are a case in point:

'…generally speaking Travellers need to link in with a given team or service based on the address that they are currently resident in….So if somebody has got chronic and enduring mental illness, it's very difficult for them to stay with a service and to ensure that they are compliant with their medication or even that they have regular appointments or that they are getting the medications that they need and are able to follow up with somebody in crisis you know or follow up with them on a regular basis or to avert or prevent any crisis arising; oftentimes that doesn't happen for Travellers, they end up presenting in crisis to an inpatient facility. Because it's the nearest one to them at that particular time, usually because they haven't attended any outpatients for a number of months or years. They haven't taken any medication over the same length of time, and they haven't got any support from any mental health service in relation to maintaining their mental well-being and it's only when it comes to a head, usually on the back of you know the family' (SSI: Service Provider).

There was agreement that addiction and drug use is related to social and environmental circumstances. These include feelings of alienation, discrimination and pressure on Traveller identity, culture and expression. Unemployment and reduced social circumstances also combine producing feelings of negativity, fatality, depression and low self worth. Travellers feel bullied by mainstream culture. Mechanisms for survival include physical prowess and standing up for one's self in the face of what they see, as overwhelming odds may be part of a coping strategy. Travellers face multiple social problems over and above those of the settled community. Allopathic or alternative medication has been a traditional response to alleviate depression and mental health problems.

Some Travellers also recognised that they had a responsibility and duty themselves to deal with drug and abuse issues and talked about the need for older Travellers to act as role models. There is also a culture of self-reliance among Travellers, i.e. not seeking assistance.

'…There is a need for it but is there a demand? There is no demand. We need to create a demand for it and create a mindset' (Addiction1).

Travellers were also themselves critical of negative aspects of Traveller culture, for example, denial of addiction. The narrative illustrated a consensus for,

'…a fundamental shift within Travellers. That is where Traveller organisations have a role to play. It is about encouragement and creating a climate whereby it's ok and it is acceptable and normal to go to seek medical help' (Addiction1).

The data indicated that
'…there was a natural resistance of families coming from the Travelling community to engage within social work…there was a natural resistance, there was someone looking in on them…Travellers were generally very sceptical particularly in the social work services…it tended to move into more of a crisis rather than resolving the difficulty…' (SSI: Service Provider).

'…It's the kind of fear if you like, that Travellers experience in terms of engaging with any structured institution' (SSI: Service Provider).

The case of Travellers presents a challenge reinforcing the distinctive needs of a particularly vulnerable community and is suggestive of the need for specific monitoring. A recent conference on the Traveller Specific Drugs Initiative, pointed to Traveller families facing crisis situations and major difficulties in accessing drug services (Traveller Specific Drugs Initiative Conference: Moving forward: Exploring Responses to Drug issues in the Traveller Community, 2005). Addiction and drug use are interrelated problems directly linked to a range of other associated factors such as social exclusion, accommodation, employment and education, (Corr, 2004; NACD, 2006; Pavee Point Centre, 2008). These emphasise the need to move beyond addiction specific strategies (focusing on pathology) to deal with related underlying (structural) influences that create, foster and promote addictive behaviour.

Traveller Experiences and Perceptions of Healthcare

The literature on the medical encounter between health professionals and lay people is replete with accounts of negative doctor/patient interaction and communication breakdown because of the expectations on the one hand of a professional culture and on the other, lay interpretations of health (Kleinman, 1980; Helman, 1978; Department of Health (ROI), 1992; Salmon, 2000; Wood, 2000). The data supports general findings that socio-economic position was also deemed to influence this (McManus, 2001). A recent review of the research into doctor/patient communication found

'consistent evidence that race, ethnicity, and language have substantial influence on the quality of the doctor-patient relationship. Minority patients, especially those not proficient in English, are less likely to engender empathic response from physicians, establish rapport with physicians, receive sufficient information, and be encouraged to participate in medical decision making' (Ferguson and Candib, 2002).

The doctor/patient experience was particularly fraught for Travellers and the use and uptake of GP services appeared to be patchy. This interface was often cited as being particularly problematic. Travellers often claimed that doctors often don't appear to listen to, or don't understand them. Many physicians were reported to adopt a physician-centered consultation sometimes with little or no attempt to adequately explain conditions or courses of treatment in a manner understood by Travellers.

'…There on Monday my father was in the local GP – went up because he wasn't well, and he went and got his prescription, within two days he had the antibiotics gone – because he couldn't read – he has a literacy problem. And the doctor never explained to him how to take them – never the chemist or the local GP, and also when they were saying a while ago, people goes to the doctor so many times that not actually explaining what's wrong with the person and lots of the times, you can't understand what they are explaining' (Women1).

Travellers tended not to be negative about individual GPs. The data suggested that some Travellers, including some men, had good personal experiences with their GP and that some GPs were very helpful but this was not the common experience. Sympathetic GPs tended to be well known to Travellers and some indicated that they travel further to be seen by these GPs.

Literacy presented a major actual barrier because health issues were not appreciated or understood, but also presented a psychological barrier since Travellers felt embarrassed, stupid and inadequate. The use of esoteric language and medical terminology, 'big words' was also deemed problematic
'…It's a part discrimination that is because one other time I had an appointment for meself and I was after being in it beforehand and I was there half –most of the day. But the next time I went I watched her – the secretary and I copped her when I was there, I was maybe the second person – my chart was the next and according as other people was coming in I got her putting mine down into the bottom – I got up and asked her where did I stand – when was the next time I was going to be called – and I said I saw you putting my chart – its discrimination and its more over – its big words like X was telling you about her mother-in-law, its big words used in the doctors and its going back to what M was telling you about her' (Women1).

The data indicated that Travellers found it difficult to articulate or explain themselves. Both men and women reported that they internalised communication breakdown as a personal problem associated with their inability to read, write or understand the doctor or chemist. The narrative indicated that men felt a sense of shame and embarrassment..

*'…We might not have the best education in the world. You go into a doctor and he is talking in bigger words and he is asking you questions on certain ways and he would say have your bowels moved and some people might know that that means did you s**t today. You get what I am saying? And they are not going to turn around and say I don't understand that because it makes you sound like a worser fool'* (Men2).

'…the doctor could have gone to his level. It can't work the other way 'round. But he [Traveller] didn't have the confidence to talk to him, you know what I mean' (Men2).
'…I would say that if you go in, a man tries to explain himself, doesn't get it quite across to the Dr, or the Dr does not pick up on it, how embarrassed is he coming away from that then being embarrassed mean his experience of that means it was a negative experience….He is talking in big words' People are embarrassed to say they don't understand them' (Men2).

Service Providers also talked about the benefits of respect and positive regard.

'…If you treat Travellers or anybody with respect and equality like everybody else and they know that's what is happening then there is never a problem' (SSI: Service Provider).

Concern regarding communication problems was not limited to the doctor/patient encounter. The narrative indicated that this frequently started at initial point of contact with receptionists who were reported to be unsympathetic, unhelpful, and prioritising other patients ahead of Travellers.

'…Also, we find with our receptionist is that I think they are not nice when you go in to them' (Women1).

'…There's a young receptionist particularly at the counter – they sort of look down on the Traveller' (Women1).

A Service Provider suggested that a model of best practice might be to provide written and verbal medical and discharge instructions to Travellers and caregivers could confirm that instructions were understood. A printout copy would mean that a family member could read these and this would aid compliance and improve safety.

The waiting room experience was also reported as being particularly tense and embarrassing. Travellers believed that the public perceived them as troublesome. Men and women reported that they felt vulnerable in the waiting area.

This was particularly the case for Traveller women who tended to bring the sick child and siblings with the expectation that the GP would also see all of the children. This may be regarded as pragmatic orientation and a responsible thing to do since many common children's illnesses are infectious often requiring treatment for siblings, also because of difficulties of transport and lack of child minding.

'… only if it is a thing that could be taken from one child to the other she would actually bring the three of them to see if it's getting passed down as well' (Women1).

The Service Provider interview data also reported that women tended to be cautious and also tended to bring children with non-serious ailments, perhaps emphasising additional information needs for Traveller women.

The waiting room experience was reported as being alienating to Travellers with no visible signs or signals that suggested comfort or security, nor an appropriate information format for those with literacy issues. Travellers reported that simple small posters for example would make a huge difference effectively welcoming them to the service and alerting others that they are welcome.

Women would commonly consult the GP on behalf of men, especially if men were in pain. Older Traveller men and women tended to be more aware of key health issues and recognised the need for medical expertise, treatment and screening, but the tendency was towards physician avoidance for men. Overall, Travellers articulated while there were instances of good practice this was not uniform and they perceived to have received an inferior service as a result.

GPs and Medical Cards

While the census data indicated that those reporting with no medical card in ROI was low, it nevertheless remained an important issue for Travellers and was regarded as symbolic of relative powerlessness. Some Travellers said that they could not understand that *'…in this day and age'* health data could not be stored centrally and accessed by different doctors in different locations.

Because of literacy issues Travellers had problems of negotiating the building access and directions as well as the protocol and bureaucracy of health services in ROI and NI.

Some Travellers reported that they did not have a GP. One respondent said,

'…I haven't got a doctor. I have been trying to get a doctor now 5 years and I still can't get one, but anyway, my daughter's experience… she tends to get an appointment in the Well Woman Centre' (Women1).

The perceptions of many health service providers was that while this was clearly a problem for some it did not appear to be the rule.

'…There certainly would not be any more difficulty than anybody else to register with us' (SSI: Service Provider).

The narratives indicated that Traveller men preferred not to attend the GP. Some also saw costs as a barrier in ROI. Some Travellers suggested that treatment was also unequal and that those with medical cards received a different standard of care and attention than those who could pay.

'…I think there's some GPs, I am talking from personal experience here, prior to when I was actually unemployed and on a medical card, attending the doctor was 50 Euro for the examination fee, right. And you'd see him on a regular basis but depending on the illness. So they'd see you on a weekly basis – the fact that you are actually paying the GP and then when you became eligible for the medical card, and because of unemployment, the doctor would then postpone the weekly visits to a monthly visit. So that was an issue' (Men1).

The point of cost and exclusion is also reported elsewhere (Local Government Improvement & Development, 2010).

Having an up-to-date medical card in ROI was key to accessing a variety of health services, including dentists. Some Travellers reported problems with accessing medical cards. Lack of, or changing postal addresses was considered a major barrier.

'…With the dentists you have to have an up-to-date medical card if you are going to a private dentist, but we find with our own families as well, lots of the GPs are holding onto the medical cards, not giving the medical cards, so therefore they can't go to the private dentist because you have to show that card to get that treatment done. So lots of GPs are holding the cards, they are out of date; there is actually a backlog in the medical cards… So lots of GPs are holding the cards, they are out of date, there is actually a backlog in the medical cards for three months and lots of the Travellers out there wouldn't even have a medical card' (Women1).

'…So it's not until you go to the doctor that you know your medical card is out of date. There is lots of the [Traveller] sites out there, including our own sites, so you are not getting your renewal form out in the post – it's the postal service as well. Travellers are always blamed for their own ill health – we don't get the same postal service and if you don't get your appointments through the post you are not going to turn up for it because you are not even aware that its even coming in. How would you know?' (Women1).

Some Trusts in England are now working on developing a personal health record that Travellers can carry with them, that can be updated by health professionals (Communities and Local Government, 2009).

In ROI the HSE are considering ways of improving access to services and the Traveller Primary Care Projects provide a number of examples of good practice, producing information on health matters for Traveller health education workshops. This is discussed further in Technical Report 1.

Dentists

Dentists were viewed as expensive and treatment tended to be for acute services such as severe toothache rather than preventative or cosmetic services or screening. Traveller women were particularly aware of the need for dental services and preventative treatment particularly for children and teenagers and were concerned about paying for such things as braces[34] .

It was also reported that dental treatment had improved and that '…dentists don't just pull teeth anymore'. Again, medical cards were needed for various dental treatments. It was also stated that traveling to NI for cheaper treatment was not a likely option because of literacy issues and form-filling (Women2).

Health Information and Communication

Triangulated data from Traveller focus groups and Service Providers point to poor communication practices as a major barrier to successful health utilisation and provision.

The narratives of Travellers stated that they had problems accessing basic health information and information on health services. Literacy was a recurring issue. Family, close relatives and friends were relied on for basic health advice that might be in/accurate and/or in/appropriate. Television and newspapers were important. Significant sources of information trusted by Travellers (particularly for those with literacy problems) were healthcare teams and Traveller health workers (ROI). Travellers who were in contact with these organisations and projects indicated that in addition to information, they crucially provided informal support and a network for information exchange and were more tuned in to the specific health issues that Travellers faced.

'…The Primary Health Care Projects go out on site and the Travellers are more aware of them and that works… they trust them more now…. They know what's happening to Travellers out there' (Women1).

Traveller projects were also said to have positive psychosocial benefits for those involved in the projects and for particularly vulnerable individuals. Concern about the closure of projects was also frequently expressed in Traveller narratives.

'…We find is lots of Travellers get their information from Traveller organisations and healthcare projects' (Women1).

'…I remember when I started healthcare that I was bringing children to the Children's Hospital with the mother, and ah I just watched, and when we were there the first, the settled people came in afterwards and they were getting brought in before we were but I had the understanding then that I could get up and say

[34] The HSE have advised that orthodontic Services (braces) are free to those with eligible clinical need.

that this woman was here first with her children – and that still happens with Travellers that X doesn't like me, doesn't understand' (Women1).

There was consensus that this was a general experience and was one repeated in other data. In NI, Paris (1995a and 1995b) also Irwin and Dunn (1996) focus on similar themes and on issues surrounding service provision. In NI Travellers are targeted by the DHSSPS NI for specific resourcing such as grant aid and support. Other initiatives have included setting up multidisciplinary teams to address health issues among Travellers.

The data confirm findings from other places (Communities and Local Government, 2009). In England the Department of Health via the Pacesetters programme has begun an innovative programme to deal specifically with Traveller health. The focus is on creating awareness of Travellers' specific needs and circumstances among healthcare professionals and also raising awareness among Travellers themselves of the potential of the healthcare workers to help them. Such models, as with the Primary Healthcare for Travellers Project in Ireland, seek to improve GP registration and access to the health services in general; and improve the recording and sharing of health information of individual community members. This includes employment of Gypsy and Traveller community members, on a seasonal basis, to act as health ambassadors between the NHS and local communities. Medical data might usefully be centrally stored on a database also held by Travellers on coded computer keys and accessed from different sites.

Travellers generally received information about health from a variety of sources. There was an agreement that while health information was more widely available, it was often inaccessible to Travellers because of literacy issues and because of a lack of effective and appropriate pathways of communication between health care professionals and Travellers. The internet was one source and was accessed by a few. Travellers mostly relied on television health programmes, literate Travellers on daily newspapers, in some cases the library. Some said they relied on computer literate relatives but this was seen as problematic because of issues of personal privacy.

Some reported that they would ask their wives if they had a concern. Younger Travellers (particularly girls) appeared to be more resourceful in terms of accessing the internet, although for many this was still not an option because of costs. Younger relatives were also relied on to access help for reading letters of appointment and translating prescriptions. These were obvious barriers and point to information needs in relation to sensitive and/or embarrassing conditions.

Preventative Health and Screening

Some Traveller men and women indicated that they were aware of lower life expectancy but tended towards immediacy and in dealing with health issues mostly as they became acute. While there is evidence that women considered family planning, men and women generally tended not to consider health planning, surveillance and follow ups. Those who did tended to be women.

'…They wouldn't go. I had 10 children and never went for a smear test or a breast check until I started overhearing the conversations here with XX and the women here. If it wasn't for the Primary Health Care

teams around the country they wouldn't hear. We never knew about the menopause …There's parts of our bodies that I didn't know about' (Women1).

'…People in the settled community, they get theirselves checked out once a year or twice a year, but Traveller men don't do that and see it's too late if anything happens and you can't do nothing about it. If then they got checked up and found there was something wrong with them, then maybe, they could do something with them. But they don't do that' (Men1).

Payment was perceived to be a major issue, even though in both jurisdictions, primary care services should be free to Travellers. The literature on the general population also supports concern over issues of affordability (O'Reilly et al., 2007).

'…There's an awful lot of Travellers out there that's even married when they are 17 or 18 and needs to have a smear test done and yet if you are under 25 years of age you have to actually pay for it. Lots of information that Travellers are getting out there now like the primary care projects that were put out on the Traveller sites' (Women1).

'…They were actually visiting sites, they would have to organise the Well Woman Clinic for lots of women to go over and have smear tests and breast examinations, because their local GP is actually charging for them…. You get charged for putting in a coil as well. All these services are actually free if you go to the Well Woman, but they are not free if you go to your local GP so that stops a lot of, particularly for women, going to the GP' (Women1)[35] .

Men felt more comfortable attending for checkups in sessions specifically aimed at them (Men2). Traveller men in one focus group reported:

'…We did groups like, where a nurse came in. A load of us came in to it. I thought that was very good… they would be more comfortable doing that than going to the doctor. I think if you were pulled into a certain area, and they do a health check now you would get more screening… You come in and you know that when you go there, they are going to be very sympathetic towards what you are saying because they are already Traveller-friendly you know what I mean' (Men2).

The data indicated that the uptake of follow-up screening services was gender-related, with women, especially in ROI, exhibiting a higher takeup of screening services. GPs also confirmed that the uptake of services for men in NI and ROI tended to be low.

Accident and Emergency and Hospitals

Travellers reported more positive experiences in the hospital. One exception was when visiting patients. Hospital rules frequently restrict the numbers of visitor to each patient However, Travellers said that they felt more secure in groups, and family and cultural expectation required that they visit sick relatives.

[35] Since the date of the data collection free cervical smear tests have been introduced in ROI through general practice for women aged 25-60 years, based on International best practice.

Travellers also expressed concern that foreign hospital staff often added a further communication barrier since they could not understand the Traveller accent.

The tendency was to avoid primary care services until health problems became acute or serious enough to necessitate the use of A & E services. In addition, Travellers perceived A & E services to be less fraught. Men and women's narrative illustrated that for men ill-health was universally equated with weakness and the inability to be able to provide for your family.

'…There are certain conditions they won't go to them – they just cope with it the best way they can' (Women: 1).

'…You see, a lot of the men, a lot of the older men won't go to a doctor because they think it is too macho… right, cause you see them coming out of the doctors, the people, people will think they, think they are weak or are sick and all that' (Men2).

'…A lot of Traveller men at a certain age are ashamed to go to doctors… a lot of people would see it as a weakness' (Men1).

'…I have a father at home he would not go to a doctor… Do you know what he would say, If you go to a doctor it would make you sick' (Men2).

Mental Health

Travellers have traditionally relied on their family networks for social and economic support. Many fear the fracturing of these bonds as a consequence of being settled. A loss of social support structures combined with distrust, a sense of anomie[36] , discrimination and low self-esteem are a potent combination likely to have implications for mental health and physical wellbeing. The loss or reduction of ties and support structures and emotional support, and the potential impact in terms of health status is well documented (Ginnety, 1993; Kawachi et al., 1997; Stanfield, 1997; Balanda and Wilde, 2003; Walker, 2008). Greenan (2009) provides a useful summary of the literature.

The data showed that while mental health services were available they were often perceived as inadequate. Travellers and Traveller advocates reported that Travellers tended not to use available counselling services, because of social stigma. They were perceived to be inappropriate for Travellers and no provision made for their specific needs. Also the Service Provider data from the key prison personnel indicate no distinction was made in terms of specific provision for Travellers.

'…Provision is not developed as a specific response to Travellers' (SSI: Service Provider).

As reported earlier, perceived discrimination was a major problem for all Travellers and there were significant accounts of this directly influencing mental health leading to feelings of depression, anxiety

[36] A personal sense of the breakdown of social norms, first described by Emil Durkheim in his seminal work on suicide, see Spaulding JA and Simpson G (Eds.) 1951

and suicide. Men agreed that discrimination causes stress and said that stress was one of the biggest things in the Travelling community. Personal experiences differed, but social stigma and discrimination were viewed as being present, constant and underlying in virtually all the qualitative data. Traveller men stated that the sense of difference and of shame begins early in a child's life and was interpreted as impacting on mental health.

Women reported feeling isolated and with periods of depression.

'…As a young person because you are emotionally embarrassed it's not all your identity but its just when people are turning you down different types of things and are ashamed to be with you, you kind of feel embarrassed and you just kind of say to yourself why are they ashamed of me I am a person the same as everyone else, I have equal rights….The way that changes things is the way that people treat you down different and I just don't understand why. There is a lot of common suicides going on in Traveller community' (Young People).

Young people also reflected on their circumstances.

'…We had one night to go out and do things like go to the pictures, go out at the weekends like. If you have a person who is really, really badly depressed and nothing to do and nowhere to go they're thinking in their head what is it I am living for then. Isn't that the kind of suicidal statement within the Traveller community. There is lots of suicides' (Young People [Girls]).

In terms of health categories men generally considered depression as a female malady but the focus group data suggested that men began to question this. Men talked openly about depression and mutual pretence in relation to denial of depression and this sparked emotive commentary in the focus groups. Traveller men's frequent narrative on macho image, and bravado was also considered by men to mask low self-esteem and relative powerlessness.

'…We are all liars at this table, and I will tell you why. An awful lot of the men are hanging themselves, taking over doses, buying the rope the whole lot…' (Men2).

*'…you all are bulls******g. We have serious mental problems and we are not dealing with it, and for starters I have often got, Jesus serious depression in my house. I must say and I have had to go for a walk, women do the same thing. I am not depressed all the time, but I go for a walk. Right go for a ramble and the whole lot, but I have had at times in my mind when things were like when things would get difficult when I would think I will buy a rope, buy a rope, you know what I mean…. you put the young lads that are hanging themselves at the minute…. they would seek no help in their own community, they didn't seek no help from the doctors, no family members seen it, no family talked about it and now we are here today with an opportunity to tell the truth and we are dancing around the fire….You are leaning against the hill and you don't see the needle yet'* (Men2).

Traditional informal counselling outlets were priests, but also for some, doctors and even surprisingly some said non-Traveller friends (the closeness of the community meant that private issues were sometimes not reported to family or Traveller friends). This also suggested that Travellers incarceration was likely to have exacerbated preexisting mental health problems.

'…The reality is for everybody…being in custody is unlikely to be positive on anybody's mental health…I have come across some very difficult cases involving Travellers, specifically in the arena of mental health…and it's possible, I assume, that being in custody, within the walls of a prison, has exacerbated their mental health condition…' (SSI: Service Provider).

Many Travellers themselves also acknowledge that the issue of service utilisation was a two-way process and that this would also require a cultural shift in Traveller attitudes.

Anxiety and embarrassment when interfacing with health services commonly emerged from the data. To attend health services was to lose face and a sense of control. This also appeared to be tied to Traveller cosmological or world outlook and reference to folk healing for example. Since this often meant that they did not seek advice and treatment at early stages there was a tendency for men and women to go straight to A & E or seek another remedy.

Mind (2010) also noted similar health issues in relation to other ethnic minority groups, the health of the Irish in England for example (see Mind www.mind.org.uk) and advocates good practice at a number of levels. What is important is the recognition of the need for and routine collection of information on health including mental health issues. Good practice involves empowering Travellers to take control. Mind point to continued consultation involving evaluating and assessing need and planning service delivery as well as outreach strategies for hard-to-reach Travellers with mental health problems.

The Departments of Health in both ROI and NI have high-level groups looking at services for Travellers and much of the current strategy looking at promotion and prevention, rather than the specific focus on sickness. This is evidence of a commitment to considering the wider social determinants impinging on the health of Irish Travellers. In NI Travellers have official recognition. However, in ROI certainly at the strategic level the HSE recognises the importance of having an ethnic identifiers in order to plan services.

'…Unless we have got robust data sure how can you plan services, it is ridiculous, it is just ridiculous' (SSI: Service Provider).

This reflects the experience of the Irish community in England who have only recently been recognised as separate from other communities and one that had specific health needs that were not addressed prior to ethnic identification (see Leavey et al., 1997; Walter, 1991)

Folk Medicine

The use of folk medicine and folk healing goes back to antiquity. We need to be cautious about romanticising Travellers and their use of folk medicine. The practice was and is more widespread than is usually imagined (Moore and McClean, 2010; Murphy and Kelleher, 1995). Traveller women and men reported a belief in and utilisation of faith healers and folk medicine. Belief in cures, charms, sometimes tied to spiritual or holy sites were important. Travellers in assessing available health resources appeared to take a pragmatic approach using services as appropriate from the popular, folk and professional traditions (Kleinman, 1980). This included utilising a range of options often depending on the type of illness.

The narrative discussed seeking folk remedies particularly for skin complaints but could also include a wider range of illness. In addition they utilised formal health services, as they deemed appropriate. The lack of interface with formal medicine because of doctor/patient communication problems, fear in an alienating environment, embarrassment at not understanding, health professional and administrator's lack of understanding or sympathy, or, perceived lack of interest (or discrimination) also meant that Travellers pragmatically resort to informal healing options. The alienating experience of formal medicine makes folk healing an even more important arena for Travellers. Travellers appear to differentiate between common ailments, skin complaints and more serious illness.

'…I think it's like if there's kids up there and they have a skin rash and they actually brang it to the doctor and the doctor gave them creams over and over again and none of the creams actually worked. What is happening out in our area then, people, the older Travellers would tell the younger generation of a cure maybe down the country – its where you go and buy the cream or get the cream off the person and you rub it onto the child for so many weeks and then it kind of heals up – it depends on what kind of sickness. Again there's cures out there for headaches, for bronchitis, whooping coughs and things because lots of times with the doctors, they don't be cured – lots of Travellers would have strong belief' (Women 1).

'…Travellers would have strong belief in lots of the cures around there' (Women1).

'…Well, a Traveller might get sick I suppose, and I suppose women as well. They believe a lot in these cures – you know, going down the country to people just to put the hand on their head, or something like that, which – for some of these conditions, that can be incurable but for ordinary people, you know what I mean, but you have to go to the hospital, you have to go to the doctors and some of them are not doing that, you know' (Women1).

While there were some sceptics, men, women and young Travellers all said they believed in cures and charms.

'…Well, it all depends on the cures now for the people down the country, like, because if its the eczema or if its warts or things like that there is cures like around the country for them, we know that there is, but when it comes to the proper sickness, you won't go for a cure, you will go to the doctor' (Women1:35).

The Traveller reference to faith healers was very strong. All men talked of importance of cures and holy wells Travellers also reported that GPs dismiss and disapprove of folk medicine. For Travellers who do not feel they have access to healthcare on the same basis as settled people folk medicine gives peace of mind.

Emerging and Novel Issues

The data suggest that many Irish Travellers have also embraced the use of modern technology such as mobile phones and these are an important means of communication and for business. Because of literacy issues computers have been considered less of a valued item. As with the general population, this can have both positive and negative aspects. Although Travellers will know others who have computers and will, if needs be, get help accessing some information via the internet.

However, the mobile technological revolution including computers has had important consequences for Traveller lifestyle. For women phones make wider contact available, but this is restricted to affordability and making ends meet is the overriding priority for most. Younger Travellers appear to be more computer literate than older Travellers. *'…There are an awful lot of young girls going to Facebook, Myspace or Bebo. It's spreading like wildfire'* (Young People1).

Service provider interviews supported this. A few Travellers reported that they had concerns about the risks and dangers in new technology and said they did not have the skills to police such things.

The unintended consequences of this technology are also important. Traveller girls for example discussed the importance in using Bebo and Facebook.

'…Bebo is some bit of sanity for young Travellers for some company' (Young People1).

'…I know a girl who met a guy on Bebo and she is getting married to him' (Young People1).

A Traveller page exists whereby Travellers can communicate with each other. The potential of this is enhanced communication with other Travellers locally and in Britain (where family members often live). The girls in the focus group communicated that at least one marriage that they new about had taken place as a result of Bebo. Since they could look for partners, exchange views on dress, where to go, and gossip, this was deemed to have had a positive mental health effect on young Traveller girls. They also talked about dangers online and abuse by non-Travellers on their page.

This may have obvious potential as an important health information outlet for Travellers young and old.

Service Providers and Policy Considerations

Throughout this report we have presented views of both Travellers themselves and Service Provider responses on various specific topics. In this section we examine specifically issues of policy relevance as touched on by Service Providers.

Civic Traveller Representation

Data from the Service Providers' semi-structured interviews recurrently support a dearth of appropriate Traveller representation at various levels of governance and indeed the need for a Traveller 'champion'.

'…Getting a political champion for it [Traveller health and social issues]… it is a difficult but really important because it will give it a little bit of drive' (SSI: Service Provider).

These champions, in the views of respondents, should also hold a position with authority to account for services of all inter-agency bodies.

'…In my view, you need to have policy that is coordinated at central governmental level, but you then need a middle layer where you have the delivery organisation to address these determinants of health, informing policy and equally being informed by what's happening on the ground. Most centrally with Travellers themselves and their support organisations' (SSI: Service Provider).

'…this was a cause worth championing, so if there was a champion or champions within the organisation...' (SSI: Service Provider).

Leadership should not only be at the level of Government, that is, top down, but should also be informed by Travellers themselves from early decision making stages, in line with good democratic participation. Leadership roles should be fostered via training and subsequent engagement support.

'…We need leadership from the Travelling community itself…' (SSI: Service Provider).

'…the big issue around language, time of meetings, how comfortable people are. If you want Travellers involved, are you going to support them in advance of the meeting…follow up with people, and mentor… whole draft of issues like that, how do they get there, what type of arrangements are made….that would obviously change the dynamic of meetings…it is much harder for them, it is a totally different way of operating…' (SSI: Service Provider).

Many recommended more Traveller engagement should be encouraged and implemented at all levels, local, regional and national.

'…there is a need for Traveller leadership at all levels…' (SSI: Service Provider).

More community engagement was needed, according to respondents, for reciprocal reasons of mutual understanding. It is only through engagement that barriers can be broken down, needs and aspiration achieved (National Institute for Health and Clinical Excellence, 2008; Ochoa and Nash, 2009). This also leads to building of trust between the Traveller community and the Service Providers.

'…There are a lot of issues coming up which the national policy would have a clue about Traveller men, you know, obviously you can name accommodation, education, discrimination and the standard ones. You can read them, they are going to be named in there but the subtlety of what's on the ground in relation to how drug use (as an example) need to be responded to, how community need to be supported and talking about it…as a first step in addressing it, instead of going in all guns blazing. A sensitive, appropriate and culturally specific response towards all these issues has to happen' (SSI: Service Provider).

At the more strategic level service providers were also aware of sensitivities when interfacing with Travellers networks and advocates so that key issues were recognised and fully addressed.

'…One of the presentations was around some of the issues around the misuse of alcohol in the Traveller community. Now that would have been an elephant in the room previously because people would have felt 'that we are letting our community down if we talk about it to you know, people who weren't kind of part of our culture'…when those kind of doors open and people feel confident enough and safe enough I suppose in a way – to actually begin to kind of talk about what is going on in their group or in their culture… That, I think, is a very good indication of again putting it up to the health services and thinking about – well what are you going to do – now that we are talking about it, to actually support what we need' (SSI: Service Provider).

There is also a need for reassessing community developments for Travellers. Community development strategies were mentioned across all departments as a method of both engaging Travellers and of promoting independence. However, this was perceived as patchy; there have been some excellent examples in some places while still poorly developed in most areas.

'…So, there are things that can be done in terms of refocusing resources both monetary and human resources, to…target what the priorities are and obviously the priorities are primary care teams and networks…And certainly the evaluations I have looked at in relation to the effectiveness of peer workers around outreaching and inreaching…I think there is pretty good evidence of their effectiveness' (SSI: Service Provider).

'…However, it is recognised that there are still massive work to be done but main barrier is related to engagement with Travellers' (SSI: Service Provider).

'…There is a need to do more community development. It has got better over the years but it has been a problem…There is problem with getting regular engagement…' (SSI: Service Provider).

It is also recognised that community development and leadership skills take time to develop.

'…even though there is a commitment to community development…it takes time to get the other leadership and grassroots participation to build up to such a stage and such a stage that ability and capability to deal with such complex issues that you deal with…' (SSI: Service Provider).

Inter-agency Fragmentation

Service Providers also reported that even though there was a good deal of inter-agency alliance, communication problems existed and represented a barrier to working effectively for Travellers. Lack of coordination can also worsen an already complex situation.

'…So, although we are kind of talking specifically about health maybe – a lot of the work we do is either with the community and voluntary sector and the NGO sector – or it is with other government departments as well' (SSI: Service Provider).

'…Sometimes the guards [ref. to Irish police force, the Gardaí] go in to arrest someone but leave the whole family in a mess. We have other responses, outreach person available to support drug user and family' (SSI: Service Provider).

Any form of public health intervention on wider societal factors, is regarded as complex, thus requiring the cooperation of all agencies.

'…There are so many policies that in theory are cross-governance, one of the things that we know about organisation...is that, across government working is not working very well...' (SSI: Service Provider).

'…What you have got is government working with (service organisation) taking central policy responsibility but it is not clear to me what does that translates to in action with the delivery organisation, how the other government departments are held accountable for their bits or what that plan is...' (SSI: Service Provider).

'…With end delivery organisations we have pockets and examples of very good practice and at different times it has been very good, but it has not been coherently joined up over sufficiently long period of time and the commitment has waxed and waned over time...so you have a disjointed picture and that needs to be tackled in the future' (SSI: Service Provider).

'…Yes, there has been progress but it is very irritating and disturbing to see how very little progress there has been...so hands on heart there has been progress but not enough, and not fast enough and not coordinated enough' (SSI: Service Provider).

It was felt that perhaps central Government should become involved in policy coordination.

'...so maybe a steering group chaired by a minister or junior minister which has...or one of the Junior Minister of Health assigned by the Minister for Health with a responsibility to deliver and he would then bring all the groups together for progress report to go back to Government...It gets the proper matter coming through, full ministerial commitment, CEO and Board commitment, senior management commitment and a couple of state agencies' (SSI: Service Provider).

Responses from the Service Providers indicated that they felt that inter-agency fragmentation and inaction caused frustration. Reference was made to a 'battle' in dealing with unresolved issues that might lead to burnout of Service Providers.

'…so the (Service Provider) will know who to contact in (governmental agencies)… they know exactly who to contact, but they find it difficult to get anything addressed for the family or for the child' (SSI: Service Provider).

'…The policy is centrally driven...at the minute, if the policy is dumped into one department, everybody else seems to think 'oh well, it is over to them then' that simply isn't good enough…and we know for complex issues like this, that they do require a range of input in order to make a sufficient difference…and the other critical thing working against us perhaps is, this is a long term issue' (SSI: Service Provider).

(Speaking with regards to an on-going water pump issue on caravan site) *'…I came in in 2002 and this is 2010, so the environment situation is very, very slow to change and that I think burns Service Providers, any Service Provider, out… it is within their remit to advocate to those agencies and to those statutory bodies on behalf of their clients and they will do that, but inaction frustrates them'* (SSI: Service Provider).

Selection of appropriate personnel dedicated to Travellers can be challenging. This is not specific to Travellers in fact and mostly relates to reluctance of Service Providers to work with disadvantaged groups because of the complexity involved. Working with Travellers requires more energy and demands more dedication from the Service Providers. In addition, due to the lack of resources, Service Providers who work with Travellers might find themselves isolated from the rest of their own department. Leadership support and support from other Service Providers with similar remit is crucial.

'…Not everyone is suitable for Traveller services; you need to choose the right person' (SSI: Service Provider).*'…and unless you have people who are committed to Traveller health and their health development, nothing's going to happen. You need the commitment; you need dedication, not somebody who is put into those positions'* (SSI: Service Provider).

Some of the Service Providers also called for more creative use of existing budgets. Only the health services have a dedicated budget through its delivery body while other agencies with a cross-sectoral remit do not necessarily have such a specific budget.

Some thought that there was a lack of *'…appropriate engagement with Travellers'* (SSI: Service Provider) and that policy should be rights and needs based and not on Government aims. This, however, has not been requested solely by the Travellers.

'…So, I think that that rights based approach if you want to put it like that… it is incredibly important – because it is about adults interacting with each other. And I think from the Traveller community point of view, one of the positive aspects I think about having the THUs and about actually interacting as a service for us, as a Health Service, with members of that community and talking to them and listening to them about

what their experience is, is that they can actually shape then what the services are going to be. And that is very, very important' (SSI: Service Provider).

'…it needs to be positioned within the context of health and wellbeing and therefore advocating the rights of Travellers but also the responsibility of governments in other departments to respond to this need' (SSI: Service Provider).

Inter-agency collaboration is more optimal at the higher level.

'...Actually, in terms of an Integrated Service Directorate, actually makes it much easier to bring the different directorates together' (SSI: Service Provider).

The issue of an ethnic identifier was regarded as important for policy on Travellers to move forward. This has been brought up by most Service Providers as important for service planning and delivery.

'…So, like it is something that we would be promoting very much… is that – embedding an ethnic identifier in terms of poor data sets, is a Government strategy' (SSI: Service Provider).

'…why are we having to do a special survey? There should be something that which is captured routinely that we can use regularly to inform decision making…' (SSI: Service Provider).

'…unless we have got robust data, sure how can you plan services, it is ridiculous, it is ridiculous…. It is very, VERY important' (SSI: Service Provider).

Services to Travellers

The funding by the Department of Health and Children (ROI) and DHSSPS NI of the Our Geels: All Ireland Traveller Health Care Study has consolidated a process of capacity building. The engagement, takeup, commitment and enthusiasm exceeded all expectations. And this has had an important impact in terms of promoting trust and enhancing social networks in a localised and all Ireland context. The strategy has also raised awareness among service providers particularly those with more limited experience of Travellers and points to the importance of collaboration between Travellers and advocates and statutory bodies to commission culturally appropriate services.

As discussed previously, social factors are considered important determinants of Traveller health by Service Providers. Education was one that recurrently almost all interviewees agreed on. Other factors include poverty, accommodation (and environment) and discrimination.

'…So, in relation to Travellers and the All Ireland Traveller Health Study for example and the health of Travellers – there was – and there is quite a bit of evidence in terms of how generally the population's health is affected by not just Health Services but by the whole determinants of health' (SSI: Service Provider).

'…Education, education, education is important, and poverty…' (SSI: Service Provider).

'…we have a responsibility to work on education, accommodation and employability...this also includes early family support...and children, early years intervention is very important, it is important that we do it for the Travellers and their families and that we do it in a sensitive way that they feel it is respectful...' (SSI: Service Provider).

'…a big pressing issue is housing and accommodation...it is ridiculous that people haven't got proper adequate standard accommodation. So, that is the most pressing thing, personally I think because from that follows schools, education, people's health, if you are living in awful circumstances, how can people think about anything, so that is, that would be, that is it really...' (SSI: Service Provider).

Service Providers also indicated that as things stand the health services environment is often unwelcoming for Travellers. Characteristics which were identified as important for effective practice were strong leadership, openness of service and services which reach out to and engage with Travellers. Characteristics judged appropriate were services not always being appointment specific and with no stigma attached, or special units which work specifically with Travellers. There was a recognition that utilisation posed specific communication challenges.

Recollecting a conversation over an issue with another Service Provider, one Service Provider related:

Service Provider X: *'…We treat everyone the same…'*

Service Provider Y: *'…It is not as simple as that. It is not all the same. The reason that there are named category… like Travellers, is that there are special requirements and special needs and where you have an attitude like 'we treat everyone the same' then that doesn't recognise that everyone is different…'*

The discriminatory practices from some Service Providers in care delivery were discussed.

'…It does exist… there is that sentiment that Travellers are less deserving, hence give them substandard services' (SSI: Service Provider).

'…Racism as one of (the) factors, but won't be said officially as they (institution) will be in trouble' (SSI: Service Provider).

'…Why would we not do it for Travelling people? What is the difference? Why do we need to use a different set of criteria? That is what we need to get to' (SSI: Service Provider).

Some also reported that academic training of health care staff was lacking when it came to Travellers. This also encompasses engagement with Travellers in research 'about' Travellers.

In terms of mental health some providers thought that there was inappropriate delivery even when the community mood was positive. There was recognition of stigma and culture bound problems in relation to Traveller lifestyle and mindset. The interview data with Service Providers also indicated there

in some instances there was a lack of basic understanding of Traveller problems.

'…and again if you extend that to people who are already socially excluded, before they get into a mental health problem there is a sort of a double social exclusion. So you are excluded because you are a Traveller or an ethnic minority and then you are excluded further because you have a mental health problem' (SSI: Service Provider).

In response to HSE orientation to the needs of Travellers, the Service Provider data indicated that some things are perceived to have changed. Some Service Providers stated that education was still a major barrier to accessing services.

'…I think probably education is the main barriers to accessing services fully and properly and is the main barrier to compliance' (SSI: Service Provider).

Others said they saw indication of change:

'…Travellers have become more savvy about what is available. My impression is that the general education level has generally improved' (SSI: Service Provider).

'…The confidence of Travellers was increasing, as was their understanding compared to the past' (SSI: Service Provider).

'…The way Travellers use the service for example. Contraception used to be an issue there was stigma to it, and having a smear test done, they were always secret and hidden but now it is more openly requested and discussed' (SSI: Service Provider).

'…They used to come with a lot of issues and try to get it done in a one-stop shop but in recent times that is not my experience. They seem to have a pretty good grasp of how the service works and what they need from it. I suspect that their appreciation of preventative services wouldn't be great' (SSI: Service Provider).

Many Service Providers nonetheless appeared to be sensitive to the specific needs of Travellers and also recognised their responsibility in communicating information effectively to them.

'…I'm sure we are pretty poor at communicating relevant information to them in a format that they would be comfortable with and find accessible. But we are probably not good at doing that with people generally anyway. In terms of communications between hospitals and primary care that's generally not good anyway. I suspect this is becoming a big issue in terms of how medical information is passed on to various sectors of the population and it is not done well, generally speaking' (SSI: Service Provider).

Travellers have been known to shy away from health preventive services. Service Providers are aware of this, yet cannot explain fully why such a phenomenon existed. One Service Provider noted that Traveller might shy away due to the method of service delivery based on 'availability' instead of a more proactive method of outreaching.

'We engage with them when they seek our service, we won't be terribly proactive going out looking for them, maybe we should…' (SSI: Service Provider).

Although follow through care appeared to be problematic, e.g.

'…There is a tendency not to follow up appointments' (SSI: Service Provider).

One Service Provider who provides preventive services also mentioned that issues around smoking with Travellers were no different than the general population and preventive services were difficult due to the more complex and chaotic lifestyle of the Travellers.

'…The prevalence of smoking is not worse than people from the same socio-economic group, they smoke because of stress and anxiety…it is difficult to for them to give them up because of their chaotic lives' (SSI: Service Provider).

The Department of Health and Children (ROI) along with Department of Health and Social Services and Public Safety (NI) funded this study and the National Traveller Reference Group was established by Traveller organisations to support the research. The Department of Health and Children is also planning with the HSE to orientate the THU and TPHCWs to the PCTs and social networks.

The Integrated Services Directorate has responsibility to oversee social inclusion services as part of the HSE delivery of services. The priority areas are to support the All Ireland Traveller Health Study, to consider the function and remit of the Traveller Health Units and how best they can be supported in terms of effectively interfacing with primary care teams and networks, and also to look at other pressing specific social inclusion services for example, addiction and alcohol and other aspects of these services that we know may have particular issues for the Traveller community (SSI: Service Provider).

'…A lot of funding goes into the acute and hospital sector…what we are trying to do is to rebalance the funding in terms of primary care. And not just the funding, we are trying to rebalance other resources' (SSI: Service Provider)

The HSE had a strategic focus on looking at access to services such as primary care services. This was one of the reasons why Traveller Health Units were set up and peer researchers trained and employed.

Cultural Rights and Representation

While the right to enjoy cultural life belongs to every person, it is cultural minorities who may be particularly vulnerable in the enjoyment of this right, as they and their interests may not be adequately represented in democratic decision-making structures. At a broad level, in their relationship with the State and local Government, as a minority, Travellers can be outvoted or marginalised by the wider community which at best does not share their priorities, and at worst may perceive their priorities as being opposed to those of Travellers. (Pavee Point and the Irish Human Rights Commission, 2008)

'…They are certainly not a homogeneous group by any means but they are a distinctive group with distinctive needs which we have failed to address and we need to address' (SSI: Service Provider).

'…The political will needs to be there...' (SSI: Service Provider).

'…You need strong advocacy – external and internal – and you need structures to enable people who are involved to have a voice...' (SSI: Service Provider).

'…political will, that's the big one I think…that's the thing that I believe that will help shift this on dramatically' (SSI: Service Provider).

'…I think that those changes in the government departments and who the new ministers are – Ministers of State are – is quite a kind of positive message, so I think that high-level group, is a very good kind of structure' (SSI: Service Provider).

'…if you want to get something significant done, you give them the evidence, and if it keeps appearing on people's desk through various advocacy groups, through questions on the Dáil, through questions on the Oireachtais committee and through internal advocacy and external group…' (SSI: Service Provider).
The various international human rights law and standards referred to in this report highlight the need to respect the right to enjoy cultural life at the early stages of policy-making and local decision-making in order to give rise to a more constructive relationship between the minority and majority communities. Effective minority participation facilitates fair processes and promotes decision-making that is sensitive to the needs of Travellers (United Nations Human Development Report, 2004; Pavee Point and the Irish Human Rights Commission, 2008).

'…but from a health service point of view, I suppose that what I feel is that because we based the strategy, our own inter-cultural strategy on some of the gold standards from other countries, then I think that is a good sort of grounding for us around what we are doing and how we deliver on it' (SSI: Service Provider).

'…then you are bringing the political system into it...where it can be chaired by a government body or government minister… at the end of the day if there is systematic blockers… then it puts the onus back on the political system...it can act as a mechanism to question the present system as well…' (SSI: Service Provider).

'…we look at Travellers not just as a strength to our society but also we see the opportunity of changing the kind of society that we have to a healthier wealthier, inclusive, stronger society that we can all feel good about' (SSI: Service Provider).

Political Representation of Travellers

The level of political representation amongst members of the Traveller community at both local and national level remains extremely low (O'Connell, 2006). A number of international treaty-monitoring bodies have expressed concern on this issue and have made recommendations in this regard. In particular, the United Nations Committee on the Elimination of Racial Discrimination has recommended that the authorities '*…consider adopting affirmative action programmes to improve the political representation of Travellers, particularly at the level of Dáil Éireann and/ or Seanad Éireann*' (Committee on the Elimination of Racial Discrimination (2005, at paragraph 22)[37] . There is a large body of international literature that discusses the optimum means of ensuring minorities are represented in the political process, with various mechanisms proposed, including reserved parliamentary seats. The purpose is to ensure that there is both representation and participation in public policy processes that impact on health and wellbeing.

In May 2008, the Council of Europe Commissioner for Human Rights noted that the level of participation of Travellers in elected bodies remains low at all levels. The Commissioner stated that he *'encourages further efforts to involve Travellers in political decision-making. Traveller communities should be adequately represented in local councils, and the possibility of reserving a specific seat for the Traveller community in the Irish parliament, perhaps in the Seanad, would merit serious consideration'* (Hammarberg, 2008).

[37] Dáil Éireann refers to the Irish parliament and Seanad Éireann refers to the Irish Senate

Our
Geels
All Ireland
Traveller
Health Study

DEPARTMENT
OF HEALTH & CHILDREN
AN ROINN SLÁINTE
AGUS LEANAÍ

Department of
Health, Social Services
and Public Safety

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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All Ireland Traveller Health Study

Our Geels

Health Service Provider Study

All Ireland Traveller Health Study

Health Survice Provider Study
Part B of Technical Report 1

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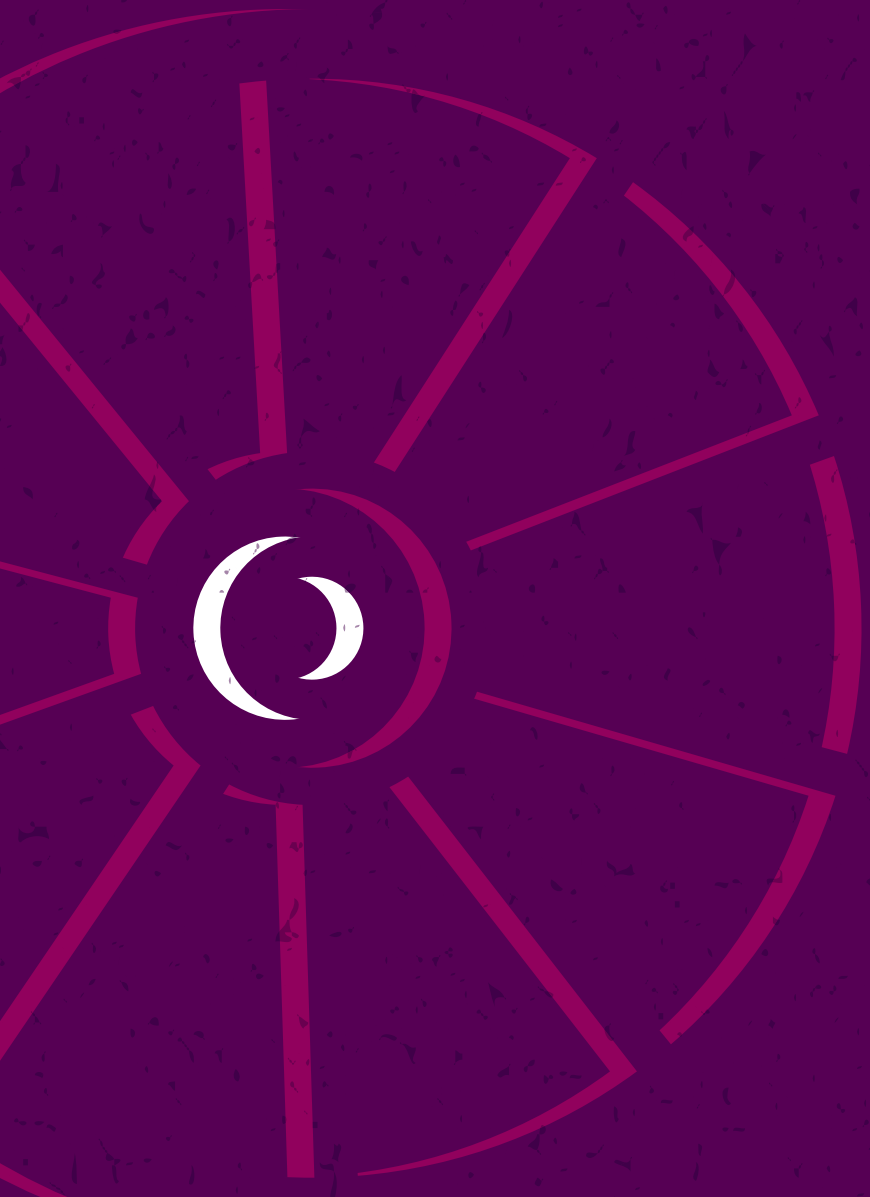
INTRODUCTION:
INTERNATIONAL EXPERIENCE OF INDIGENOUS MINORITY HEALTH



Measures to overcome barriers to Health Promotion and Health Care for Minority Populations

There is a strong international literature on the health needs of minority groups ranging for example from the Inuits of Canada (Young, 2003; Health Council of Canada, 2005) the Aboriginals and Maoris of Australia and New Zealand (Carson *et al.,* 2007; Davis *et al.,* 2006; Anderson *et al.,* 2006; Pincock, 2008) Blacks, Hispanics and Native Americans in the United States (Rhoades, 2003; Roubideaux, 2005; Kaufman *et al.* 1998) and South America, immigrant Asian and West Indian populations in the United Kingdom (Davey-Smith *et al.,* 2000; Smaje and Le Grand, 1997), and Roma and Gypsy populations in Europe (Parry *et al.,* 2007; Cemlyn, 2009; Vokó *et al.,* 2009; Hajioff and McKee, 2000). Indeed the Irish in Britain and the US have been documented extensively also (Clucas, 2009; Kelleher *et al.,* 2006; Scally, 2004; Garrett, 2002; Abbotts *et al.,* 1997). This literature concerns itself with several aspects of catering equitably for distinctive groups and individuals across society. At the level of provision of services, barriers may be encountered such as language and norms of behaviour. Health care providers may fail to appreciate nuances of understanding that lead to an inadequate treatment experience. Access may be impeded by resources, eligibility and means of payment. Cultural aspects such as family and social support and the differing needs of men and women are all considerations. Practicalities in infrastructural delivery, including mobile populations and distance from care, are all important. Krieger (2003) emphasises the need to distinguish factors associated with race and culture from those of economic disadvantage, to ensure an adequate understanding of policy and practice. Services must find a fine line between ensuring all are treated equitably and fairly on the one hand and imposing on the other hand a 'one size fits all' model that consciously or unconsciously has the effect of hindering participation or adequate care for a vulnerable individual (National Economic and Social Forum, 1996; Quirke, 2001). This literature clearly has resonances for the assessment of health services from Travellers' perspective, using increasingly well recognised quality assessment procedures of norms of care such as those of the Picker Institute in the United Kingdom, employed in 2007 in the first general consumer satisfaction survey undertaken by the Republic of Ireland's HSE (Boilson *et al.,* 2007).

There is international evidence of disparities in indigenous health:
'Indigenous peoples have low standards of health. Their poor health is associated with poverty, overcrowding, poor living conditions, social exclusion, discrimination and this is compounded by reduced access to health care and prevention. Some indigenous groups as they move from traditional to transitional and modern lifestyle to transitional and modern lifestyles,, are rapidly acquiring lifestyle diseases, such as obesity, cardiovascular disease and type 2 diabetes, and physical, social, and mental disorders linked to misuse of alcohol and of other drugs. Indigenous people should be encouraged, trained and enabled to become increasingly involved in overcoming these challenges' (Gracey and King, 2009)

Indigenous minorities across the world tend to be much poorer than the majority populations, they experience higher rates mortality for all causes of deaths and higher rates of chronic disease, such as hypertension, obesity, heart disease and suicide. These disparities continue to increase and this suggests that the level of response and societal intervention has not been effective in addressing these inequalities. The Inverse Care Law (those who are most in need of medical care are least likely to receive it - see Tudor Hart, 1971) also applies as they have less access to services. In a systematic review by

Marrone (2007), of 37 studies on current status of healthcare access and utilisation among indigenous people in North America, Australia and New Zealand, she found a low utilisation of quality health care services, as many of the indigenous communities were isolated in remote rural areas and had limited access to primary, secondary or specialised health care. She noted that Native populations in North America have a significantly higher prevalence of type 2 diabetes than white majority populations. Even when other factors such as socio-economic status; health insurance and chronic conditions are controlled for the racial and ethnic disparities are still apparent (Marrone, 2007; Davey Smith, 2000).

According to the Indian Health Services report (Indian Health Service, 2006), the American Indian and Alaskan native people have long experienced lower health status and higher mortality than the general US population, native children and youths are more than twice as likely to die in the first 4 years of life as is the general population, infants die at a rate of 8.9 per 1,000 live births, compared with 7.2 per 1,000 for the US all-races population. They also have lower life expectancy that is almost 6 years less than that of the US all-races population (Indian Health Service, 2006). Their age-adjusted death rates are greater than for the general US population for: Alcoholism - 740% higher; Tuberculosis - 500% higher; Diabetes - 390% higher; Injuries - 340% higher; Suicide - 190% higher. The leading cause of death for American Indian and Alaska Native men is coronary heart disease, followed by accidents, chronic liver disease, suicide, diabetes mellitus, cerebrovascular disease, and pneumonia/influenza (Rhoades, 2003). American Indian and Alaska Native men are also less likely to seek medical help and more likely to pursue risk-taking behaviours such as binge drinking and failure to use seat belts. Their prevalence of type-2 diabetes among children is higher than that of any other ethnic group. Evidence suggests that these disparities exist due to inadequate education, disproportionate poverty, discrimination in the delivery of health services, and cultural differences. These are broad quality-of-life issues rooted in economic adversity and poor social conditions.

A 1993 study of mortality and social class in New Zealand examined the changes in mortality rates for Maori and non-Maori men over a 10-year period. Between 1975-7 and 1985-7 the researchers found a 54% decline in Maori mortality and a 23% decline in non-Maori mortality, however the Maori mortality rate was still 2.8 times the non-Maori rate. Differences in social class explained a significant proportion of this difference, but a substantial portion remained attributable to ethnicity alone (Pearce *et al.,* 1993). Earlier studies which examined differences in mortality rates between Maori and non-Maori males also found that while much of the difference was attributable to social class, a substantial proportion could only be explained by ethnicity (Pearce *et al.,* 1983; 1984).

Health Status of Indigenous Peoples

'On current rates, one-third of young indigenous men aged 15 will be dead before age 60, compared with 8% in the Australian population. This four-fold increase in risk of death, is largely due to excess mortality from such causes as ischaemic heart disease, suicide, and Type 2 diabetes. Its reduction must be a priority for indigenous health services' (Pearce et al., 1993).

The burden of disease and injury in Aboriginal and Torres Strait Islanders, cardiovascular disease and mental disorders were the major disease categories in the indigenous Australian population in 2003, accounting for 32% of the disease burden. Chronic respiratory disease, diabetes, and cancers were the next three leading causes, each accounting for 8% of the total indigenous Australian disease burden. The disease burden caused by cancer in the indigenous population (8%) is much lower than the burden it causes in the total Australian population (19%) because indigenous people are dying earlier, from other causes.

The life-expectancy gap between indigenous Australians and non-indigenous Australians is 17 years. It is a gap that compares especially poorly with similar societies, such as New Zealand, where the gap between indigenous and non-indigenous life expectancies is 7 years (Australian Indigenous Health Infonet 2009)

Because more is now known about the causes of ill-health in indigenous communities, something can be done about the effects.

'In terms of the health gap, 50% of it is due to the fact that when indigenous people get sick they die much more quickly. The other 50% is due to risk factors. We need to provide access to quality care, focus prevention around tobacco control and diet, and invest in a health workforce.' (Vos *et al.,* 2007).

A review of the access of Pacific people[1] to health services in New Zealand (Young, 1997) acknowledges the limited information available and draws together what research has shown about Pacific people's health service usage. The paper highlights the barriers of acceptability of health services to Pacific people in addition to geographical and financial barriers to access (Young, 1997).

According to Marrone (2007), following a review of 138 population based studies on ethnicity, culture and race, longitudinal studies suggest that self-reported racism precedes negative health outcomes. The strongest associations were observed for mental health outcomes (psychological stress and depression) and health-related behaviours (substance abuse, alcohol abuse and smoking). Rates of substance and alcohol abuse are substantially higher among indigenous groups, which have also been shown to be related to increased rates of suicide. A review of suicide rates among indigenous

[1] This minority population were originally from the Polynesian Islands and migrated to New Zealand (NZ) for work, they are now living in NZ for three generations and are NZ citizens, but feel they get treated differently because of their ethnic origins, they are comonly referred to as Pacific people or Pacificians and data is now disaggregrated to identify their health experience in New Zealand.

populations in Canada, the U.S., New Zealand and Australia found that suicide rates among indigenous young adult men were the highest out of all age groups and were 2 to 5 times higher than the general population (Marrone, 2007). Moreover, studies have shown that among American Indians and Alaska Natives perceptions of racial discrimination and marginalisation are related to substance use and depressive symptoms.

The study on the Health Status of Gypsies and Travellers in England (Parry *et al.,* 2004) found that *'There is now little doubt that health inequality between the observed Gypsy Traveller population in England and their non-Gypsy counterparts is striking, even when compared with other socially deprived or excluded groups and with other ethnic minorities'.*

Parry found that the impact of smoking, education and access to GP service is important. She noted that educational disadvantage of Gypsy Travellers was the single most marked difference between Gypsy Travellers and other ethnic minority and social excluded populations. The findings suggested that the roles played by environmental hardship, social exclusion and cultural attitudes which emerge from the qualitative study are consistent with the finding there is a health impact of being a Gypsy Traveller over and above other sociodemographic variables (Parry *et al.,* 2004).

The findings of this study demonstrate that the health needs of Gypsy Travellers are not being met through current services and strategies in the UK. Models of good practice would suggest the need to work in partnership with Gypsy Traveller communities in the planning and delivery of healthcare, employ dedicated or specialist health workers, include Gypsy Travellers in the NHS ethnic monitoring system, and provide training to health providers to ensure cultural competence (Parry *et al.,* 2004).

The study suggested that any policy or initiative developed for Gypsy Travellers should include a commitment to a community development approach to improve the capacity of Gypsy Travellers to participate equally in their healthcare. It also suggested more dialogue between users and providers might address some of the barriers, and that the use of patient-held records would also improve the continuity of care. Health service should be culturally appropriate and take cognisance of Gypsy Traveller educational disadvantage and poor levels of literacy, for example in the form of audiotapes or DVDs to communicate health education messages. This study also suggested that the model of good practice developed in Traveller Primary Health Care projects in Ireland would be a good model to emulate (Parry *et al.,* 2004).

Barriers to Access

Evidence suggests that there is an under-utilisation of health services by ethnic minorities (Blofeld, 2003; Aspinall and Jacobson, 2004; Equalities Review, 2007). There is a concern that some Service Providers justify this under use by making assumptions about the level of reliance of people from minority ethnic groups on family support and informal caring, the level of knowledge and understanding of services and sometimes the evidence is ignored about potential service users: which describes prejudice, discrimination, distrust and a lack of appropriate services (Grewal and Lloyd, 2002; McLean *et al.,* 2003).

A study undertaken by the Commission for Health Improvement in the UK found ethnic differences in service users rating of their care in terms of: access and coordination of services; the environment in which services were provided; the provision of information; their involvement in healthcare decisions; the level of choice regarding care pathways; consideration of their physical and emotional needs and being treated with respect (Raleigh *et al.,* 2004).

Lack of Data

Anecdotal evidence and qualitative data point to continuing poor experiences and access to healthcare, quantitative evidence has been hampered by a failure of National Health Service institutions to collect ethnicity data on patients, at both hospital and primary care level (King's Fund, 2006 a,b). A great deal of activity has clearly been aimed at improving access to health services for Black, Minority and Ethnic (BME) groups; however, evaluating the outcome of projects has been difficult due to the absence of this data. Up to a third of hospital data is still not coded, according to the London Health Observatory, and few GP surgeries routinely collect information about their patients (Aspinall and Jacobson 2004). According to Sproston,

'Organisations need to gather information about and from minority ethnic communities as well as trying to provide information to them. Effective methods for identifying the needs of people from these communities and monitoring how well these are met are needed; collecting information about the make-up of populations served by means of published data and effective monitoring can highlight which groups an organisation may be neglecting and which may be over-represented' (Sproston and Mindell, 2006).

Barriers to Healthcare

In a review paper on the potential barriers to the use of health services among ethnic minorities (Scheppers, 2006) the authors concluded that potential barriers occurred at the patient level, provider level and system level:

- The barriers at patient level were related to the patient characteristics: demographic variables, social structure variables, health beliefs and attitudes, personal enabling resources, community enabling resources, perceived illness and personal health practices.
- The barriers at provider level were related to the provider characteristics: skills and attitudes.
- The barriers at system level were related to the system characteristics: the organisation of the healthcare system.

They noted that
'ethnic minority patients seem to be confronted with barriers when using health services. Yet, care providers are often oblivious to these barriers, although they may share to some extent the burden of responsibility for them. In order to enlighten care providers, as to the potential pitfalls that may exist, there is a need to explore the different factors in the creation of the barrier' (Scheppers, 2006).

According to Szczepura (2005) in most healthcare systems it is acknowledged that black and minority ethnic (BME) populations have until now experienced poorer health and barriers to accessing certain services. The author undertook a number of reviews examining the evidence on population diversity and variations in service uptake, health outcomes, effective patient communication, and involvement in decision-making, and noted that
'at the same time it is recognised that 'disparities often present as inequalities in quality', in other words even if certain groups use a service they may still experience inferior quality care and, therefore, poorer access'.

In a systematic review by Atikson on access to and uptake of National Health Services (NHS) by ethnic minorities (Szczpura, 2005; citing Atikson *et al.,* 2001), 3 dimensions of equitable access were identified: to culturally appropriate information; to services that are relevant, timely, and sensitive to the person's needs; to use the health service with ease, and having confidence that you will be treated with respect.

Szczepura concluded that equal access is clearly linked to equal care. She found evidence in her review which suggests that access-related factors may be the most significant barriers to equitable care. Szczepura defines 'equitable care' as care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographical location and socio-economic status. Thus monitoring of services that limits the measure to utlisation of care is inadequate if it does not consider the process, participation and outcome from that service. Healthcare systems have to be 'equality proofed' to ensure that they can ensure that marginalised populations have equality of access, participation and outcome to health care.

Quality of Services

The Lancet published two studies in 2006, which explored the outcomes of minority groups engaging with the health service. The first is a cross-sectional assessment on the quality of hospital care experienced by Maori patients in New Zealand. The findings suggested that there was a significant difference in the care the Maori patients received when compared with the majority population in New Zealand, and this disparity persisted after controlling for age, other socio-demographic factors and case mix (Davis *et al.,* 2006).

The second was a matched cohort study on cancer diagnosis, treatment, and survival in indigenous and non-indigenous Australians. It found that non-indigenous cancer patients survive longer than indigenous ones, even after adjustment for stage at diagnosis, cancer treatment, and greater comorbidity in indigenous cases Valery *et al.* (2006). It concluded that better understanding of cultural differences in attitudes to cancer and its treatment could translate into meaningful public-health and clinical interventions to improve cancer survival in indigenous Australians.

The reviews pointed to the need for increased surveillance, policy research, capacity building and community engagement and partnership in dealing with indigenous health issues (see Anderson *et al.,* 2006; Davis *et al.,* 2006; Smylie *et al.,* 2006; Stephens *et al.,* 2006).

Cultural Competence and Quality of Services

Quality is clearly linked to equality of access, participation and outcomes care, as it is accepted that 'access-related factors may be the most significant barriers to equitable care' (Szczepura, 2005). Equitable access has been defined as 'care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographical location and socio-economic... Thus, definitions of "access" that are limited to service uptake or "receipt of care" are clearly inadequate unless they also consider the process of accessing care, and the quality of care received by ethnic minority groups' (Szczepura, 2005).

Although language barriers may be important, it is also well reported that various dimensions of culture can influence successful healthcare delivery to ethnic minority populations. Cultural differences are also likely to be more persistent than language needs in immigrant groups. Cultural dimensions might include: patients' health; healing, and wellness belief systems; how illness, disease, and their causes are perceived; and the behaviour of patients/consumers seeking health care, and their attitudes toward healthcare providers.

Communication and Health Information

The evidence shows that poor levels of communication have a negative effect on access to services and on relationships between service users and professionals. Problems with communication include language barriers and poor engagement with networks used by minority ethnic groups. People from minority ethnic communities are often unaware that services are available because they have never seen or heard information about them (Katbamna *et al.,* 2000). Using a single approach to reach minority ethnic groups does not work for the same reasons it would not work in the general population. Making English language materials easy to read and including pictures can also improve access for many people from minority ethnic communities, as well as people with limited literacy and people with learning disabilities (Aspinall and Jackson, 2004; Mir *et al.,* 2001; Robinson, 2002). Posters, leaflets and outreach activity that advertise this support need to be made widely available through networks used by minority ethnic communities, for example, via community centres, places of worship and local shops, or services used by members of these communities (Aspinall and Jackson, 2004).

However, if a person is not literate in his or her own language, access to a professional who can give verbal advice in an appropriate language is needed (Betancourt *et al.,* 2002). Access to this person should be as easy as possible and should not rely only on professional referral (Mir and Din, 2003).

In ethnographic research by King and Wilson (1998) with Aboriginal health professionals and Aboriginal clients with diabetes, they found both the health professionals and the clients had limited access to relevant and useful information about the effect of diabetes on Aboriginal clients, families and communities. In order to support the stated priority given to Aboriginal health care, it was recommended that tertiary nursing courses must include content on how to deliver services in a way that is acceptable to Aboriginal people. The researchers also found that Aboriginal people do not receive culturally acceptable health care from non-indigenous providers, and concluded that until Aboriginal people are employed as part of the health team limited progress will be made in improving

the health of Aboriginal people with diabetes (King and Wilson 1998). In recent years public policy has moved to address theses disparities more generally to reduce health inequalities. We discuss some exemplars further below.

Strategies to Address Barriers

Community Health Workers/Link Workers

Following a review of the role of link-workers in primary care, Gillam and Levenson (1999) found that Community Health Workers (CHWs) can make a valuable contribution to community development and, more specifically, can improve access to and coverage of communities with basic health services. There is robust evidence that CHWs can undertake actions that lead to improved health outcomes, especially, but not exclusively, in the field of child health. Link Workers can also help in interactions with the primary healthcare team, local authority, and benefits agencies. They bridge the gap between Service Providers and patients, which may sometimes require challenging the more purely biomedical model of health that concentrates on the biological process and disease end point, rather than the wider social and economic causal factors determining that disease or illness. Many Link Workers have been assertive in challenging individual and institutional racism in the UK National Health Service (NHS). The literature suggests that Link Workers can make a valuable contribution in many services, such as new patient health checks, women's health, and mental health. TCHWs are effective in increasing access to health services, increasing knowledge and promoting behaviour change. The value of a clearly defined role for TCHWs was also explored and validated by Lehmann and Sanders (2007), see also Technical Report 1 for a fuller review of Irish models of practice.

Pillinger (2003) for instance identified the following best practices in terms of quality of service:

- Participative approaches where quality is linked to choice and autonomy of users.
- User empowerment and involvement in planning.
- Improvements that include meaningful and practical methods of assessment implemented with the participation of both users and front-line staff.
- Quality objectives that are relevant and adaptable to local settings.
- Quality standards developed in partnership with staff, management and users.

Social Inclusion

A socially inclusive society is defined as one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity. Social exclusion is the process of being shut out from the social, economic, political and cultural systems which contribute to the integration of a person into the community (Cappo, 2002).

Social inclusion describes the structures and dynamic processes of inequality among groups in society. Social exclusion refers to the inability of certain groups or individuals to participate fully in daily life due to structural inequalities in access to social, economic, political and cultural resources. These inequalities

arise out of oppression related to race, class, gender, disability, sexual orientation, immigrant status and religion. Indeed, it has been argued that 'being excluded from social groups ranks among the most aversive of human experiences' (Labonte 2004).

Empowerment and Engagement

Wallerstein, in his report on the effectiveness of empowerment strategies to improve health and reduce health disparities, showed that empowering initiatives can lead to health outcomes and that empowerment is a viable and effective public health strategy.

'Empowerment is recognised both as an outcome by itself, and as an intermediate step to long term health status and disparity outcomes' (Wallerstein and Duran, 2006).

Meaningful, ongoing, respectful engagement recognises the importance of technically effective services but also takes into account the values, experiences and priorities of minorities. 'Engagement' can be explained by contrasting it with 'consultation'.

Consultation occurs when Government or a health authority says: 'Here is the problem, here is the solution. Do you have any comments?' Engagement occurs when Government or a health authority lays out the problem and invites people to participate in understanding the problem, possibly redefining the problem, and coming up with the solutions to the problem.

More and more research supports the engagement process as critical for making community-based legitimate and sustainable decisions. Giving Indigenous people and ethnic minorities a meaningful voice will lead to better health policy decisions and those decisions will be more sustainable (Wallerstein and Duran, 2006).

Handheld Records

In Scotland, the National Resource Centre for Ethnic Minority Health (NRCEMH), in consultation with Gypsy/Travellers have developed a Patient Record of Personal Health which is a handheld record to be carried by the individual. It is hoped that this will greatly improve the continuity of care for Gypsy/Travellers and that, in turn, this will have a significant impact on the inequalities of health experienced by Gypsy/Travellers.

The hand-held record system will only be successful if Gypsy/Travellers make use of it and if is readily accepted by the NHS. Training is being offered training on the use of handheld records to NHS staff and other NHS partners.

Additional Training for Health Professionals

Another strategy to improve the responsiveness of existing health services to underserved groups is to provide additional training to mainstream health workers. US research (Pediatrics) used a controlled study to evaluate a programme of additional training given to paediatric clinic staff serving low income communities in New York (Evans *et al.,* 1997). The training was given to staff in the prevention,

screening, diagnosis and treatment of asthma, with particular emphasis on ways to enhance family management of asthma. In each of 2 years follow-up the intervention clinics showed greater improvement on all measures of access, continuity and quality of care (Evans *et al.,* 1997). Primary health care services are in principle more easily accessible to minority groups in local areas; such strategies include making available healthcare professionals of the same ethnicity as the client group, recruiting ethnic or bilingual lay health workers, and providing additional training for existing health workers.

Aboriginal workers and community members naturally tend to act as enablers, facilitators, and advocates for their communities (these are the 3 key roles of a health promotion worker identified in the Ottawa Charter[2] WHO, 1997). Building community competency should be a key component of health promotion work.

There is some early evidence of health gains, such as reduced rates of child mortality and communicable disease in certain communities for specific subpopulations. These community studies are beginning to show that gains occur where there is collaboration between Aboriginal and Torres Strait Islander communities and Governments and comprehensive services supported by adequate and sustained funding.

Models of Good Practice at Policy Level

Aboriginal Health Services Plan 2007-2010, 3 July 2007

'Aboriginal health is holistic. It encompasses health determinants, is supported and fostered by Indigenous knowledge and know-how, and is community-based and driven. It includes health/mental health and addiction needs that call for accessible programs and services for all ages and stages of life'
Lisa Tabobondung, Executive Director: Aboriginal Health.

National Strategic Framework for Aboriginal and Torres Strait Islander Health

The National Aboriginal Health Strategy (NAHS), released in 1989 was built on extensive community consultation to produce a landmark document that set the agenda for Aboriginal health and Torres Strait Islander health. It is being cited here for good practice because it uses a holistic approach incorporating health determinants and indigenous knowledge. The NAHS is extensively used by health services and service providers and continues to guide policy makers and planners – it has been acknowledged as a model of good practice in international literature. The National Strategic Framework is a complementary document that builds on the 1989 NAHS and addresses approaches to primary health care and population health within contemporary policy environments and planning structures.

[2] The Ottawa charter originated from the World Health Assembly in 1977. It highlighted the role of health promotion in addressing health inequalities.

This National Strategic Framework is based on a commitment to the following principles:

- Cultural respect: ensuring that the cultural diversity, rights, views, values and expectations of Aboriginal and Torres Strait Islander peoples are respected in the delivery of culturally appropriate health services.
- A holistic approach: recognising that the improvement of Aboriginal and Torres Strait Islander health status must include attention to physical, spiritual, cultural, emotional and social wellbeing, community capacity and governance.
- Health sector responsibility: improving the health of Aboriginal and Torres Strait Islander individuals and communities is a core responsibility and a high priority for the whole of the health sector. Making all services responsive to the needs of Aboriginal and Torres Strait Islander peoples will provide greater choice in the services they are able to use.
- Community control of primary health care services: supporting the Aboriginal community controlled health sector in recognition of its demonstrated effectiveness in providing appropriate and accessible health services to a range of Aboriginal communities and its role as a major provider within the comprehensive primary health care context.
- Supporting community decision-making, participation and control as a fundamental component of the health system that ensures health services for Aboriginal and Torres Strait Islander peoples are provided in a holistic and culturally sensitive way.
- Working together: combining the efforts of Government, non-Government and private organisations within and outside the health sector, and in partnership with the Aboriginal and Torres Strait Islander health sector, provides the best opportunity to improve the broader determinants of health.
- Localised decision making: health authorities devolving decision making capacity to local Aboriginal and Torres Strait Islander communities to define their health needs and priorities and arrange for them to be met in a culturally appropriate way in collaboration with Aboriginal and Torres Strait Islander health and health-related services and mainstream health services.
- Promoting good health: recognising that health promotion and illness prevention is a fundamental component of comprehensive primary health care and must be a core activity for specific and mainstream health services.
- Building the capacity of health services and communities: strengthening health services and building community expertise to respond to health needs and take shared responsibility for health outcomes. This includes effectively equipping staff with appropriate cultural knowledge and clinical expertise, building physical, human and intellectual infrastructure, fostering leadership, governance and financial management.
- Accountability: including accountability for services provided and for effective use of funds by both community-controlled and mainstream health services. Governments are accountable for effective resource application through long-term funding and meaningful planning and service development in genuine partnership with communities. Ultimately, Government is responsible for ensuring that all Australians have access to appropriate and effective health care.

This document draws together nationally agreed strategies to address specific health problems, state and territory policies and plans and the national collaborative policy and planning frameworks within which Aboriginal and Torres Strait Islander health programs are managed today.

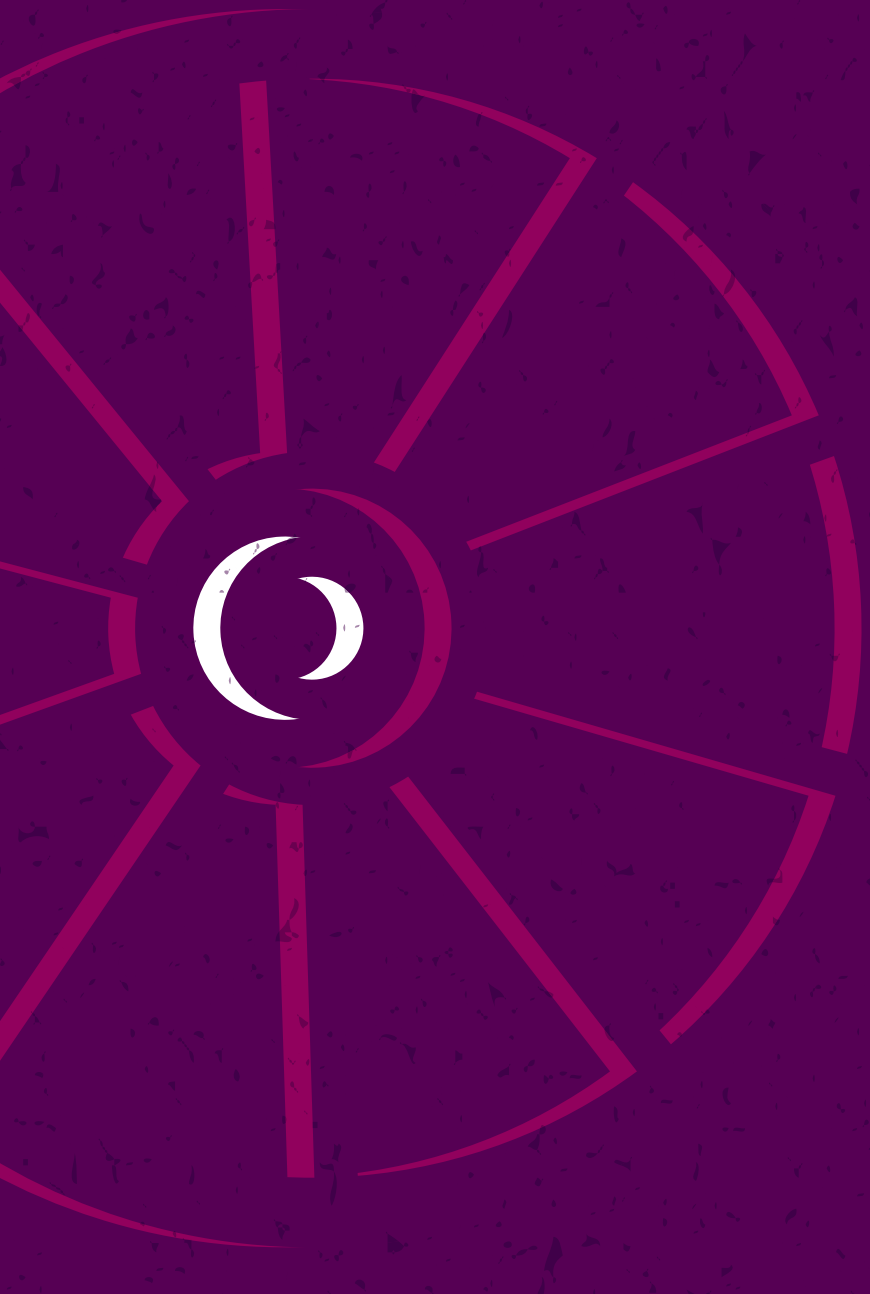
Learning from the Literature Review

We learn from this examination of the International literature that indigenous populations and ethnic minorities continue to experience extreme disparities in their health status. The evidence emerging from review of the literature that is relevant to Traveller health is that there are key elements that should be engaged in by services providers and policy makers if they want to address the continuing health inequalities experienced by minority groups. We summarise these key elements below as the need for:

- increasing prioritisation of the needs of the minority populations
- commitment from all stakeholders to reduce the gap in health inequalities that exist
- ethnic and cultural identifiers in all data sets, to disaggregrate data for monitoring and evaluation
- development and implementation of equality proofing systems which monitor health access, participation and outcome for minority populations
- a social determinants approach to address the health status of minority communities (see details and reference to the social determinants in Technical Report 1)
- intersectoral working with key agencies and stakeholders
- projects to support the capacity building, engagement and empowerment of local communities
- partnership working with minority communities and Non government Organisations (NGOs) in the planning, monitoring and evaluation of services
- the training and employment of indigenous health workers from local community
- targeted services to be complementary to and not a replacement for mainstream services
- a culturally competent and quality health service
- the development of culturally appropriate education materials
- training of service providers on minority cultures
- national, regional and local policies and strategies to be developed following consultation and engagement with local communities and NGOs

These findings resonate with the discussion in Technical Report 1, to which we refer the reader for further information.

METHODOLOGY:
HEALTH SERVICE PROVIDER QUANTITATIVE STUDY



This chapter reports on the Health Service Provider sub-study of the 'Our Geels': All Ireland Travellers Health Study. The aim of this study was to explore the issues that arise for Health Service Providers in providing for the Traveller community, to explore how this impacts on Traveller health and to make recommendations for improvements in same.

Setting/Sampling

This sub-study sought to undertake up to 500 Health Service Provider interviews by Computer-Assisted Telephone Interview (CATI) in ROI and NI. The methodology was purposeful and quota-based. Potential respondents were identified and recruited as follows to ensure that an acceptable quota of respondents by both professional groupings and regions was achieved.

Identification of Potential Respondents

Based on the scoping exercise conducted prior to the Traveller census when potential participants/families for the census were identified we estimated that 32% of Traveller families in the ROI were in the HSE West region, 28% were in the HSE South area and 40% were in the HSE Dublin North East and Dublin Mid-Leinster areas combined (16% in DNE and 24% in DML). In order to achieve a broad geographical spread the recruitment of potential respondents in the Republic was proportionate to this. In addition, on a more micro level where possible, the number of letters sent to Health Service Providers in each Local Health Office (LHO) region was also proportionate to the number of families identified in that area prior to the census.

The sample was purposeful and included the health professionals ranked as the top 10 accessed by Travellers in the recently completed health utilisation study. In consultation with the HSE Liaison and Implementation Group this list was further refined to include mental health services which, depending on regional variation, were either Psychiatric Hospital or Outreach Psychiatric Services. Table 3B. 1 below illustrates the maximum number of Health Service Staff required to be recruited in ROI as outlined at the outset of the study stratified by professional grouping.

The HSE provided the UCD team with a list of potential respondents broken down by both LHO area and professional groupings which was later amended and supplemented in consultation with members of the HSE Liaison Group in order to achieve a balance of respondents from each of the professional groupings across the 4 HSE Areas.

In NI the recruitment of potential respondents was also based on achieving a broad geographical distribution. In order to achieve this, and given the smaller sample size, the interviews to be completed in NI were divided among the 5 Social and Health Care Trusts. A Principal Investigator in each Trust provided a list of potential respondents supported by the Stakeholder Group in NI.

Table 3B. 1: Sample breakdown for the Republic of Ireland

	TOTAL	HSE West (32%)	HSE South (28%)	HSE Dublin North East (16%)	HSE Dublin Mid Leinster (24%)
GP staff	130	42	36	21	31
Hospital staff	100	32	28	16	24
Mental Health Services	25	8	7	4	6
PHNs	50	16	14	8	12
CWOs	25	8	7	4	6
Social workers	25	8	7	4	6
Dental services	20	6	6	3	5
Management/ policy	25	8	7	4	6
Total ROI	400	128	112	64	96

Again the sample was purposeful and included the health professionals ranked as the top 10 accessed by Travellers in our recently completed health utilisation study. The sample stratified by service for NI can be seen below in Table 3B. 2. It differed slightly from the sample in the ROI due to regional variation. That is, as the role of Community Welfare Officer is specific to the ROI and due to the small sample size in each of the groupings by Trust a category named 'other community services' supplemented the Community Welfare Officer and Social Workers categories. In addition, the Public Health Nursing grouping was replaced by the Northern equivalent grouping of Health Visitors.

Table 3B. 2: Sample breakdown for Northern Ireland

	Belfast Trust	Southern Trust	S.E. Trust	Western Trust	Northern Trust	TOTAL
GP Staff	6	6	6	6	6	30
Hospital Staff	5	5	5	5	5	25
Mental Health Services	1	1	1	1	1	5
Health Visitors	3	3	3	3	3	15
Other Community Services	3	3	3	3	3	15
Dental Services	1	1	1	1	1	5
Management/ Policy	1	1	1	1	1	5
Total	20	20	20	20	20	100

Recruitment

Service Providers who did not provide services to Travellers were automatically included in the sample as we had no a priori means of identifying those who do or do not provide services to Travellers. We were aware of this at the outset an d included a small series of questions to elicit information from these providers as to why they do not provide for Travellers. Our sampling strategy was based on a quota sampling basis using a sliding scale process illustrated in Table 3B. 3 below. Our aim was to obtain a 60% minimum representation in each professional grouping.

Table 3B. 3: Sliding scale strategy employed to obtain our quota of 500 attained sample

Pre-contacted health service providers	Estimated response rates	Attained sample
650	78%	507
700 (+50)	72%	500
800 (+100)	65%	520
850 (+50)	60%	510
1000 (+150)	50%	500

For ease of interpretation: Taking row 1 the shaded row as an example, if 650 Service Providers were contacted and a response rate of 78% was reached, we would have 507 completed interviews. If however this was not attained another 50 service providers (row 2) could be contacted and a response rate of 72% would result in 500 attained interviews.

Recruitment was a 2-stage process. Named respondents in both NI and ROI were identified as discussed above and were then contacted by letter from the UCD team explaining the purpose and procedures of the study and inviting participation. Respondents were invited to return the letter indicating whether they would or would not take part as well as indicating a time when it would be convenient for them to be interviewed. All replies including reasons for refusing were documented as appropriate. Reminder letters were sent up to a maximum of 2 times. The list of providers (with names and contact details) who agreed to participate was given to our trained researchers who conducted the interviews.

If there was no response to the letters of invitation we posted hardcopy questionnaires with the final reminder letters, asking respondents to complete in hard copy if preferable. This enhanced participation as some respondents viewed this as being more convenient than the CATI call and returned the hard copy. In addition those who did not respond to any of the letters were followed up by telephone to offer a last opportunity to participate or establish a reason for non-response.

Interviewers

The interviews were undertaken by post-graduate students on the Master of Public Health and PhD programmes in UCD, many of whom were health professionals themselves. Inhouse training and induction were provided by the study team on the instrument and the methodology. All the interviewers had to achieve a standard level of competency before being allowed to conduct live interviews. Having received feedback from stakeholders the study team completed several in-house pilots for face validity. Each interviewer also completed pilot calls prior to going live with the survey. The paper questionnaires were entered into the CATI system by these interviewers.

Questionnaire

Following a literature review of previous Traveller studies and discussions with the TSG and the Principal Investigator Group, a draft questionnaire was drawn up and circulated to a number of health professionals inclusive of doctors, nurses, dentists and pharmacists. Detailed comments were obtained from them, and used to develop a revised instrument. The questionnaire was developed with the following criteria in mind:

- To cover major themes identified in previous studies.
- To cover major themes identified in the scoping exercise with Service Providers.
- To cover major themes identified in the current "Our Geels" study.
- To be suitable for a mainly closed instrument.
- To keep respondent burden low.

The final questionnaire contained the following sections -
Section A: capturing the demographics of the Service Provider.
Section B: capturing whether respondents provided services to Travellers and if not why not.
Section C: exploring access to and use of services by Travellers.
Section D: exploring perceptions in relation to the health status of Travellers.
Section E: exploring the interface between Travellers and the service.
Section F: exploring the provision of services to Travellers.

When the final questionnaire was drafted an electronic version was created using the computer software HTMLJqueryPHPMYSQL .

Interviews

The data collection period commenced 22nd February, 2010 and was completed by 11th June, 2010. Calls were made between 8 a.m. and 8 p.m. Three call-stations were established in a dedicated survey room in UCD and operated on a rotational basis of morning, afternoon and evening based on the volume of respondents to be called on any given day. Calls lasted approximately 15-20 minutes. The outcomes of all calls were recorded.

Response

The number of potential respondents contacted was determined by the importance of ensuring that the response rate did not fall below a representative level. Saturation of information in light of triangulation with the other sub-studies was also a key consideration, that is, if the same information was recurring then the quota cell was deemed acceptable for that category of respondents. Ultimately 720 potential respondents were contacted as a minimum overall response rate of 50% and a minimum quota of 60% in each of the professional groupings and by region were sought.

- 54 of these individuals were considered unavailable to participate due to being on leave, retired, no longer in post or not having received correspondence in relation to the study. Of the remaining 666 respondents:
- 53.4% (356 Health Service Providers) completed the survey.
- 4.6% (31 Health Service Providers) responded that the questionnaire was not relevant to them as they did not have enough experience of working with Travellers to answer the questions. 29.9% (199 Health Service Providers) refused to take part.
- 11.1% (74 Health Service Providers) did not respond/could not be reached. The overall response rate is 356 out of 666 eligible respondents (53.4%), or 356 out of 592 successfully contacted (60.1%).

The number of achieved interviews based on the original quota sought is illustrated in Table 3B. 4 below, stratified by area and professional grouping.

Data cleaning

Most of the CATI data required little extra work post interview. The 3 open-ended questions did require significant checking and re-coding. These were questions 36, 50, and 54. In addition, 2 further variables, were added, one to distinguish self-completion vs. CATI responses, and one to identify which of the 5 Areas (the 4 HSE Administrative Areas and Northern Ireland) the respondents were from. A further set of additional 'skip' variables have been added to indicate responses which have been skipped in the questionnaire as a result of branching, i.e, where some respondents skip questions not of relevance to them.

Table 3B. 4: Achieved Interviews

Professional Grouping	Northern Ireland			HSE West			HSE South			HSE DNE			HSE DML			TOTALS		
	OQ	AI	%	OQ	AI	%	OQ	AI	%	OQ	AI	%	OQ	AI	%	OQ	AI	%
GP	30	8	27	42	24	57	36	23	64	21	17	81	31	17	55	160	89	56
Dentists	5	4	80	6	8	133	6	2	33	3	3	100	5	3	60	25	20	80
Other community services	15	* 9	60	16	19	118	14	9	64	8	7	87	12	13	109	65	57	87
Public Health Nurses / Health Visitors	15	* 11	73	16	18	112	14	15	107	8	9	112	12	13	109	65	66	101
Mental Health Services	5	4	80	8	4	50	7	5	71	4	4	100	6	5	83	30	22	73
Management / Policy	5	5	100	8	5	62	7	1	14	4	6	150	6	4	67	30	21	70
Hospital Staff	25	12	48	32	28	87	28	23	82	16	10	62	24	8	33	125	81	65
TOTAL	100	52	52	128	106	83	112	78	70	64	56	87	96	63	66	500	356	71

OQ denotes the number originally proposed as the maximum in each grouping.

AI denotes the number of achieved interviews

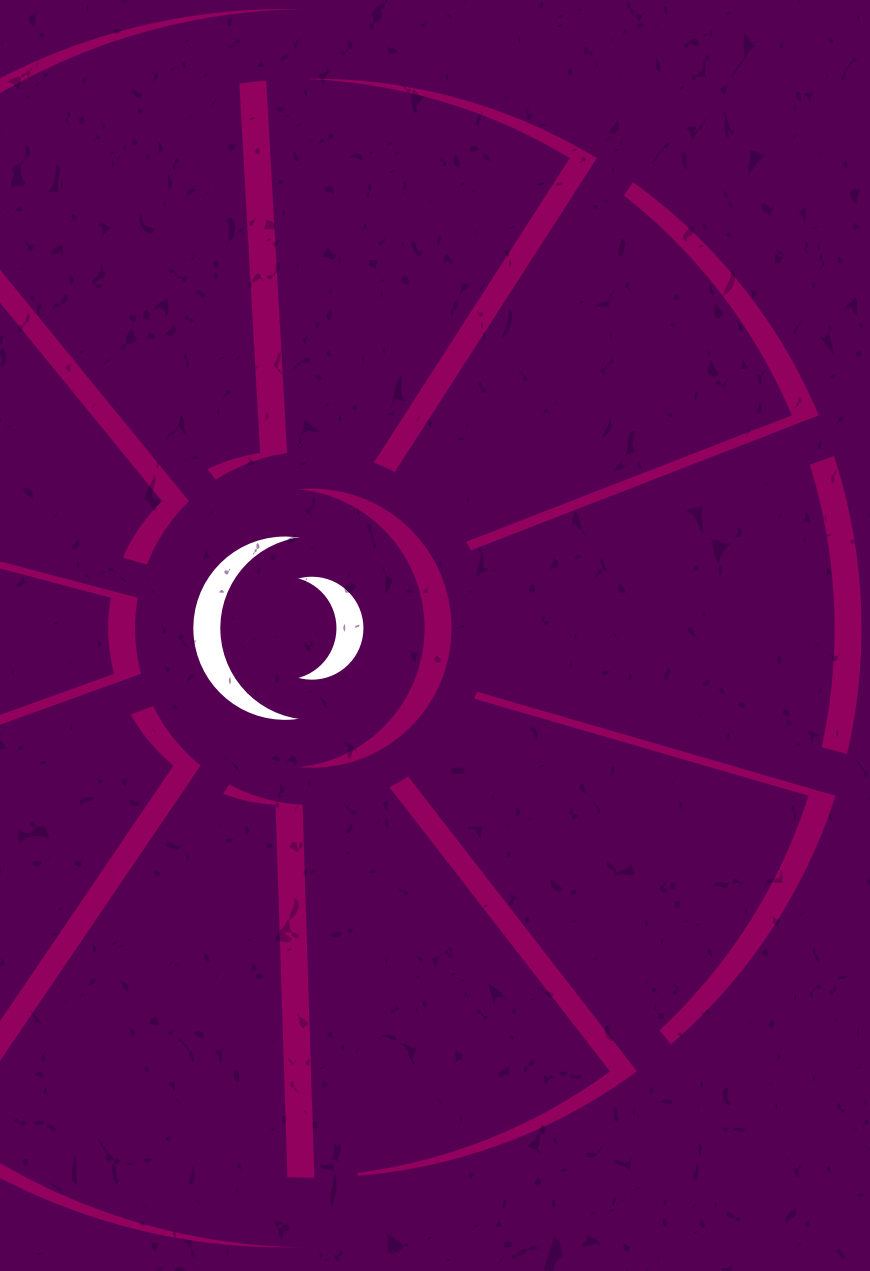
% denotes the percentage of the original quota achieved

* 5 of respondents in the community services grouping in the North were coded as Health Visitors for branching purposes.

Hospital staff interviewed included consultant doctors in key services such as A & E, Paediatrics, Obstetrics and Cardiology, nurses at various levels of responsibility and management staff.

A response of 'Refused' was recorded for 6 of the respondents in the data in relation to their professional grouping. These are included in the table above under the professional grouping given to the study team at the recruitment phase.

RESULTS



Data is presented in the results section in sequence according to question. Exact numbers are given for each response - note these may vary as totals depending on whether the question was skipped by the respondent. Short comments on some specific tables are provided to support interpretation. Sections B to F inclusive are broken down by region (NI) Northern Ireland and (ROI) the Republic of Ireland and by three categories 'GPs', 'Hospital Staff' and a third category 'Other Professional groupings'. Testing for significance was undertaken according to jurisdiction and professional category as appropriate. Analysis was undertaken using the R statistical software programme. Both a chi-squared test for association, and a Monte-Carlo based test, an analogue of a Fisher's exact test for association, in each table are reported.

Section A: Demographics

A very diverse group of professionals responded to the survey (Table 3B. 5). GPs and nurses constituted the largest groups, as per the quota methodology. They all had substantial experience (Table 3B. 6), with similar median experience of 21-25 years in each main occupational group (data not shown). The majority were female (63.8%, data not shown), in keeping with the general health services demographic in both jurisdictions.

Table 3B. 5: Respondent: Occupation

Occupation	n
GP	81
GP (NI)	7
Hospital Staff	77
Mental Health Services	22
Public Health Nursing Service	56
Health Visiting	16
Community Welfare Officer	24
Social Worker	26
Dental Services	19
Management/Policy	20
Refused	6
N/A	2

Table 3B. 6: Respondent: Working experience

Working experience (in years)	n
0-5 years	7
6-10 years	26
11-15 years	36
16-20 years	45
21-25 years	64
26-30 years	74
30+ years	102
Refused	0
N/A	2

Table 3B. 7: Respondent: Age group

Age group	n
20-30	3
30-40	61
40-50	135
50-60	129
60-65	16
65+	9
Refused	1
N/A	2

Table 3B. 8: Respondent: Location of practice

Location	n
City	61
Suburb	59
Town	178
Village	11
Other	42
Refused	3
N/A	2

Table 3B. 9: Total size of GMS list served (for GPs in ROI)

	exc. 0s
Min	100
1st Quartile	1,000
Median	1,215
Mean	1,606
3rd Quartile	1,850
Max	11,000
N/A	281

Table 3B. 10: Total size of list served (for all GPs)

	exc. 0s
Min	230
1st Quartile	2,120
Median	3,500
Mean	4,888
3rd Quartile	7,423
Max	11,400
N/A	349

Table 3B. 11: Number of beds in the main hospital serviced (for hospital staff only)

	Inc. 0s	exc. 0s
Min	0.0	25.0
1st Quartile	52.0	147.5
Median	200.0	250.0
Mean	345.6	443.5
3rd Quartile	320.0	400.0
Max	900.0	900.0
N/A	279.0	296.0

Section B: Service to Travellers

Table 3B. 12: Provision of service to Travellers

	Never	Rarely	Sometimes	Often	Very Often	Refused	n
Total (n)	9	25	87	116	109	2	348
Overall (%)	2.6	7.2	25.0	33.3	31.3	0.6	
NI (%)	6.5	13.0	19.6	50.0	10.9	0.0	46
ROI (%)	2.0	6.3	25.8	30.8	34.4	0.7	302
Pearson's Chi-squared test $\chi^2 = 18.1349$, df = 5, p-value = 0.002782			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 18.1349$, df = N/A, p-value = 0.01099				
Total (n)	9	25	84	114	108	2	342
Overall (%)	2.6	7.3	24.6	33.3	31.6	0.6	
GP (%)	2.3	8.0	10.2	28.4	50.0	1.1	88
Hospital Staff (%)	6.6	7.9	26.3	36.8	21.1	1.3	76
Other (%)	1.1	6.7	30.9	34.3	27.0	0.0	178
Pearson's Chi-squared test $\chi^2 = 33.0959$, df = 10, p-value = 0.0002625			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 33.0959$, df = N/A, p-value = 0.0004998				

Most respondents had some experience of provision of services to Travellers. Relatively few respondents reported rare contact and just 2.6% said they never provided services to Travellers.

Note the substantial difference between the NI respondents and the ROI respondents, with half of the NI respondents reporting that they were providing services 'Often' whereas the ROI respondents had a wider spectrum of experience. GPs were the provider group with most frequent contact; half of this group very often provided services.

Section C: Access to and Use of Services

In this section respondents were asked a number of questions in comparison to non-Traveller patients in similar social circumstances. Overall, respondents considered Travellers less likely than other patients to access and use their services. There were significant differences between different service user groups, in how they categorised Travellers, and these patterns were not the same across all the questions asked. In particular Travellers were felt not to engage as effectively with preventive services, except antenatal services. Travellers were also more likely to receive prescriptions. Traveller men tended to present later than is desirable.

In comparison to non-Traveller patients in similar social circumstances, are Traveller patients more or less likely to:

Table 3B. 13: Understand how to use your service?

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	19	123	153	34	13	7	2	351
Overall (%)	5.4	35.0	43.6	9.7	3.7	2.0	0.6	
NI (%)	0.0	39.6	45.8	8.3	0.0	6.3	0.0	48
ROI (%)	6.3	34.3	43.2	9.9	4.3	1.3	0.7	303
Pearson's Chi-squared test $\chi^2 = 10.9322$, df = 6, p-value = 0.0905			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 10.9322$, df = N/A, p-value = 0.08796					
Total (n)	19	119	152	33	13	5	2	343
Overall (%)	5.5	34.7	44.3	9.6	3.8	1.4	0.6	
GP (%)	4.6	29.9	51.7	8.1	5.8	0.0	0.0	87
Hospital Staff (%)	4.0	35.5	43.4	9.2	1.3	4.0	2.6	76
Other (%)	6.7	36.7	41.1	10.6	3.9	1.1	0.0	180

Overall, most respondents thought Travellers were either about as likely (43.6%) or less likely (35.0%) to understand how to use their service. There was a wider range of opinion on this issue in ROI than NI. Patterns of opinion on this issue were similar according to professional grouping.

Table 3B. 14: Understand how to access your service?

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	14	96	154	62	17	6	3	352
Overall (%)	4.0	27.3	43.8	17.6	4.8	1.7	0.9	
NI (%)	0.0	27.1	47.9	16.7	2.1	6.3	0.0	48
ROI (%)	4.6	27.3	43.1	17.8	5.3	1.0	1.0	304
Total (n)	14	93	153	60	17	4	3	344
Overall (%)	4.1	27.0	44.5	17.4	5.0	1.2	0.9	
GP (%)	4.6	20.5	48.9	17.1	9.1	0.0	0.0	88
Hospital Staff (%)	4.0	23.7	46.1	18.4	1.3	4.0	2.6	76
Other (%)	3.9	31.7	41.7	17.2	4.4	0.6	0.6	180
Pearson's Chi-squared test $\chi^2 = 19.5288$, df = 12, p-value = 0.07654			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 19.5288$, df = N/A, p-value = 0.06447					

Overall there was a spectrum of opinion on whether Travellers understand how to access respondents' services. Just under half of respondents rated Travellers as about as likely to understand as others (43.8%) and just over a quarter (27.3%) as less likely. This did not differ across jurisdictions.

There was a trend of borderline significance for the Other Professionals category to find Travellers less likely to understand (31.7% compared to 20.5% of GPs and 23.7% of hospital staff).

Table 3B. 15: Keep appointments

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	51	168	83	20	0	9	1	332
Overall (%)	15.3	51.0	25.0	6.0	0.0	2,.7	0.3	
NI (%)	14.3	64.3	14.3	0.0	0.0	7.1	0.0	42
ROI (%)	15.5	48.6	26.6	6.9	0.0	2.1	0.3	290
Pearson's Chi-squared test $\chi^2 = 10.5487$, df = 5, p-value = 0.0611			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 10.5487$, df = N/A, p-value = 0.08996					
Total (n)	50	165	82	20	0	7	1	325
Overall (%)	15.4	50.8	25.2	6.2	0.0	2.1	0.3	
GP (%)	16.7	51.2	26.2	5.9	0.0	0.0	0.0	84
Hospital Staff (%)	12.9	61.4	12.9	4.3	0.0	7.1	0.0	70
Other (%)	15.8	46.2	29.8	7.0	0.0	0.0	0.0	171
Pearson's Chi-squared test $\chi^2 = 23.3007$, df = 10, p-value = 0.00969			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 23.3007$, df = N/A, p-value = 0.008496					

Travellers were considered less likely (51.0%) or much less likely (15.3%) than others to keep appointments. There was no significant difference according to jurisdiction in likelihood of Travellers keeping appointments compared with others. While all health professionals score Travellers less likely than the settled community to keep appointments, hospital staff (61.4%) assess Travellers as less likely to do so than other patients to a significantly greater degree than the other two professional groupings.

Table 3B. 16: Be on time for appointments

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	35	136	125	16	2	12	1	327
Overall (%)	10.7	41.6	38.2	4.9	0.6	3.7	0.3	
NI (%)	14.3	40.5	31.0	4.8	0.0	9.5	0.0	42
ROI (%)	10.2	41.8	39.3	4.9	0.7	2.8	0.4	285
Total (n)	34	132	125	16	2	10	1	320
Overall (%)	10.6	41.2	39.0	5.0	0.6	3.1	0.3	
GP (%)	8.4	48.2	38.6	2.4	1.2	1.2	0.0	83
Hospital Staff (%)	10.0	42.9	31.4	5.7	0.0	8.6	1.4	70
Other (%)	12.0	37.1	42.5	6.0	0.6	1.8	0.0	167
Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 18.4853, df = N/A, p-value = 0.07846								

Respondents considered Travellers to be less likely (41.6%) or much less likely (10.7%) than other patients to be on time for appointments and there was no significant difference according to jurisdiction or professional grouping. Hospital staff had the widest spectrum of opinion on this issue.

Table 3B. 17: Comply with instructions about treatments

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	25	149	131	7	1	14	3	330
Overall (%)	7.6	45.1	39.7	2.1	0.3	4.2	0.9	
NI (%)	4.3	38.3	42.6	4.3	0.0	10.6	0.0	47
ROI (%)	8.1	46.3	39.2	1.8	0.4	3.2	1.1	283
Total (n)	25	145	130	7	1	11	3	322
Overall (%)	7.8	45.0	40.4	2.2	0.3	3.4	0.9	
GP (%)	2.9	50.0	46.6	1.1	0.0	0.0	0.0	88
Hospital Staff (%)	9.6	37.0	37.0	4.1	0.0	9.6	2.7	73
Other (%)	9.9	46.0	38.5	1.9	0.6	2.5	0.6	161
Pearson's Chi-squared test χ^2 = 25.3335, df = 12, p-value = 0.01332			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 25.3335, df = N/A, p-value = 0.007996					

Compliance with instructions about treatments was again rated as less likely or much less likely by appreciable numbers of respondents, 52.7% overall (42.6% NI and 54.4% ROI). GPs on this question assess Travellers as being less likely to comply with instructions than other groups, but the overall assessment suggests some difficulties with perceived compliance by all professional groups, with the hospital category showing the widest range of opinion.

Table 3B. 18: Attend for follow-up at your service

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	30	159	117	16	1	9	1	333
Overall (%)	9.0	47.7	35.1	4.8	0.3	2.7	0.3	
NI (%)	11.1	44.4	37.8	0.0	0.0	6.7	0.0	45
ROI (%)	8.7	48.3	34.7	5.6	0.4	2.1	0.4	288
Total (n)	30	155	117	15	1	7	1	326
Overall (%)	9.2	47.5	35.9	4.6	0.3	2.1	0.3	
GP (%)	5.8	51.7	36.8	4.6	1.1	0.1	0.0	87
Hospital Staff (%)	6.9	48.6	33.3	2.8	0.0	6.9	1.4	72
Other (%)	12.0	44.9	36.5	5.4	0.0	1.2	0.0	167

Attendance for service follow-up was rated as less likely (47.7%) or much less likely (9.0%) by a majority of respondents (55.5% NI and 57.0% ROI) and was not significant according to jurisdiction. There was a significant pattern according to Professional grouping, the 'Other' category having the highest probability of considering attendance much less likely.

Table 3B. 19: Attend referral appointments from your service

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	27	155	105	14	0	20	2	323
Overall (%)	8.4	48.0	32.5	4.3	0.0	6.2	0.6	
NI (%)	4.9	51.2	36.6	0.0	0.0	7.3	0.0	41
ROI (%)	8.9	47.5	31.9	5.0	0.0	6.0	0.7	282
Total (n)	27	151	105	13	0	18	2	316
Overall (%)	8.5	47.8	33.2	4.1	0.0	5.7	0.6	
GP (%)	11.5	54.0	32.2	1.2	0.0	0.2	0.0	87
Hospital Staff (%)	4.2	47.9	32.4	1.4	0.0	12.7	1.4	71
Other (%)	8.9	44.3	34.2	7.0	0.0	5.1	0.6	158
Pearson's Chi-squared test χ^2 = 20.4537, df = 10, p-value = 0.02524			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 20.4537, df = N/A, p-value = 0.02399					

A majority (56.4%) of respondents thought Travellers less likely or much less likely to attend referral appointments from their service. There was no difference according to jurisdiction in respondents' assessment of Travellers' likelihood of attending referral appointments. GPs (65.5%) were significantly more likely than other groups to consider Travellers would not attend, and only just over one third of respondents felt Travellers and the general community had similar patterns of behaviour.

Table 3B. 20: Make use of preventative services

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	72	171	49	3	0	24	2	321
Overall (%)	22.4	53.3	15.3	0.9	0.0	7.5	0.6	
NI (%)	16.7	42.9	23.8	2.4	0.0	14.3	0.0	42
ROI (%)	23.3	54.8	14.0	0.7	0.0	6.5	0.7	279
Pearson's Chi-squared test $\chi^2 = 8.3899$, df = 5, p-value = 0.1360			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 8.3899$, df = N/A, p-value = 0.1254					
Total (n)	71	167	48	3	0	22	2	313
Overall (%)	22.7	53.3	15.3	1.0	0.0	7.0	0.6	
GP (%)	20.7	64.4	12.6	1.2	0.0	1.2	0.0	87
Hospital Staff (%)	26.1	40.6	10.1	2.9	0.0	18.8	1.5	69
Other (%)	22.3	52.9	19.1	0.0	0.0	5.1	0.6	157
Pearson's Chi-squared test $\chi^2 = 32.0134$, df = 10, p-value = 0.0003984			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 32.0134$, df = N/A, p-value = 0.000499					

Travellers were considered by a very clear majority of respondents as being less likely (53.3%) or much less likely (22.4%) than others in similar circumstances to avail of preventive services. There was a significant difference according to professional grouping; however, with hospital staff more likely to report that they did not know, although a majority in all professional groupings thought Travellers less likely to so do.

Table 3B. 21: Make use of treatment for long-term illness

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	15	114	114	15	4	20	7	289
Overall (%)	0.5	39.4	39.4	5.2	1.4	7.0	2.4	
NI (%)	2.5	37.5	35.0	7.5	0.0	15.0	2.5	40
ROI (%)	5.6	39.8	40.2	4.8	1.6	5.6	2.4	249
Total (n)	15	112	113	15	4	17	6	282
Overall (%)	5.3	39.7	40.0	5.3	1.4	6.0	2.1	
GP (%)	4.6	42.5	49.4	2.3	1.1	0.0	0.0	87
Hospital Staff (%)	6.2	32.8	32.8	7.8	4.7	14.1	1.6	64
Other (%)	5.3	41.2	37.4	6.1	0.0	6.1	3.8	131
Pearson's Chi-squared test $\chi2 = 29.0991$, df = 12, p-value = 0.003809			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 29.0991$, df = N/A, p-value = 0.002499					

There was a spectrum of response to the question of Travellers making use of treatment for long-term illness, though with substantial numbers considering it less likely (39.4%) and with no significant pattern across jurisdictions. There was a significant difference in response according to Professional groupings, again with high rates of 'don't knows' (14.1%) among hospital staff.

The next two questions related to use of antenatal and postnatal care.

Table 3B. 22: Make use of antenatal care services

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	15	69	99	15	5	25	4	232
Overall (%)	6.5	29.8	42.6	6.5	2.1	10.8	1.7	
NI (%)	3.2	25.8	41.9	6.5	0.0	22.6	0.0	31
ROI (%)	7.0	30.3	42.8	6.5	2.5	9.0	2.0	201
Total (n)	15	67	98	15	4	22	4	225
Overall (%)	6.7	29.8	43.5	6.7	1.7	9.8	1.8	
GP (%)	5.8	24.4	59.3	8.1	1.2	1.2	0.0	86
Hospital Staff (%)	2.1	25.5	34.0	6.4	2.1	29.8	0.0	47
Other (%)	9.8	37.0	33.7	5.4	2.2	7.6	4.3	92
Pearson's Chi-squared est with simulated p-value (based on 2000 replicates) χ^2 = 46.3083, df = N/A, p-value = 0.0004998								

This question shows a wide range of response but marks a more positive shift in that respondents thought it about as likely (42.6%) or more likely (6.5%) that Travellers would make use of antenatal services. There was no significant difference according to jurisdiction.

There was a highly significant difference according to professional grouping in answering this question, with relatively high rates of 'don't know' from hospital staff (29.8%) not engaged in obstetrical care.

Table 3B. 23: Make use of postnatal services

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	12	81	92	15	4	27	6	237
Overall (%)	5.1	34.2	38.8	6.3	1.7	11.4	2.5	
NI (%)	2.9	26.5	41.2	5.9	0.0	23.5	0.0	34
ROI (%)	5.4	35.5	38.4	6.4	2.0	9.4	3.0	203
Total (n)	12	78	92	15	4	24	5	230
Overall (%)	5.2	34.0	40.0	6.5	1.7	10.4	2.5	
GP (%)	4.6	33.7	48.8	9.3	2.3	1.2	0.0	86
Hospital Staff (%)	6.5	30.4	28.3	0.0	2.2	32.6	0.0	46
Other (%)	5.1	35.7	37.8	7.1	1.0	8.2	5.1	98

Again, compared with the responses to other questions, Traveller women seemed to come close to meeting the expectation of Service Providers for this type of care, with 38.8% rating it about as likely and 6.3% more likely that Travellers would make use of postnatal services. This may suggest something about how Traveller women use antenatal care in contrast to other services.

Table 3B. 24: Make use of any screening services which you offer

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	25	113	75	10	2	13	3	241
Overall (%)	10.4	46.9	31.1	4.1	0.8	5.4	1.2	
NI (%)	17.9	35.7	35.7	0.0	0.0	10.7	0.0	28
ROI (%)	9.4	48.4	30.5	4.7	0.9	4.7	1.4	213
Total (n)	25	111	74	10	2	10	1	233
Overall (%)	10.7	47.6	31.7	4.3	0.8	4.3	0.4	
GP (%)	10.3	59.8	26.4	3.5	0.0	0.0	0.0	87
Hospital Staff (%)	16.7	31.2	29.2	6.2	2.1	14.6	0.0	48
Other (%)	8.2	44.9	37.8	4.1	1.0	3.1	1.0	98
Pearson's Chi-squared test $\chi^2 = 29.2276$, df = 12, p-value = 0.003645			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 29.2276$, df = N/A, p-value = 0.002999					

Travellers were considered by a majority of respondents (57.3%) as either less likely or much less likely to make use of any screening services offered, with a highly significant pattern according to professional grouping, GPs rating it as least likely compared to the other groupings.

Table 3B. 25: To be prescribed medicine

	Much less likely	Less likely	About as likely	More likely	Much more likely	Don't know	Refused	n
Total (n)	6	22	167	55	10	17	13	290
Overall (%)	2.1	7.6	57.6	19.0	3.4	5.9	4.5	
NI (%)	0.0	0.0	65.8	18.4	0.0	10.5	5.3	38
ROI (%)	2.4	8.7	56.4	19.1	4.0	5.2	4.4	252
Total (n)	6	22	165	54	10	15	11	283
Overall (%)	2.1	7.8	58.3	19.1	3.5	5.3	3.9	
GP (%)	0.0	4.6	58.6	31.0	4.6	0.0	1.1	87
Hospital Staff (%)	1.5	5.8	73.9	7.2	1.5	8.7	1.5	69
Other (%)	3.9	11.0	49.6	17.3	3.9	7.1	7.1	127
Pearson's Chi-squared test $\chi^2 = 37.6269$, df = 12, p-value = 0.0001767			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 37.6269$, df = N/A, p-value = 0.0009995					

Likelihood in being prescribed medication marks a change in trend of response, a majority in both jurisdictions thinking it either about as likely (65.8% NI and 56.4% ROI) or more likely (18.4% NI and 19.1% ROI) than anyone else. There was however a highly significant difference according to professional grouping, a clear majority of hospital staff (73.9%) thinking this about as likely as anyone else.

The next 4 items asked respondents to indicate in their experience, in general, at what stage do members of the Travelling community present for care:

Table 3B. 26: Men from the Traveller community

	Very Early	Early	About the Right Time	Late	Very Late	Don't know	Refused	n
Total (n)	2	4	33	88	95	18	8	248
Overall (%)	0.8	1.6	13.3	35.5	38.3	7.2	3.2	
NI (%)	0.0	0.0	16.0	44.0	28.0	12.0	0.0	25
ROI (%)	0.9	1.8	13.0	34.5	39.5	6.7	3.6	223
Total (n)	2	4	33	85	95	16	6	241
Overall (%)	0.8	1.7	13.7	35.3	39.4	6.6	2.5	
GP (%)	0.0	0.0	18.8	47.1	31.8	2.4	0.0	85
Hospital Staff (%)	2.4	7.3	7.3	34.2	29.3	14.6	4.9	41
Other (%)	0.9	0.9	12.2	27.0	48.7	7.0	3.5	115
Pearson's Chi-squared test $\chi^2 = 35.0687$, df = 12, p-value = 0.0004567			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 35.0687$, df = N/A, p-value = 0.0009995					

Table 3B. 27: Women from the Traveller community

	Very Early	Early	About the Right Time	Late	Very Late	Don't know	Refused	n
Total (n)	5	39	121	78	14	12	6	275
Overall (%)	1.8	14.2	44.0	28.4	5.1	4.7	2.2	
NI (%)	0.0	16.1	45.2	25.8	3.2	9.7	0.0	31
ROI (%)	2.1	13.9	43.9	28.7	5.3	3.7	2.5	244
Total (n)	5	39	121	74	14	10	4	267
Overall (%)	1.9	14.6	45.3	27.7	5.2	3.7	1.5	
GP (%)	1.2	12.8	65.1	18.6	2.3	0.0	0.0	86
Hospital Staff (%)	1.8	11.1	33.3	35.2	9.3	7.4	1.8	54
Other (%)	2.4	17.3	37.0	30.7	5.5	4.7	2.4	127
Pearson's Chi-squared test $\chi^2 = 27.3606$, df = 12, p-value = 0.006854			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 27.3606$, df = N/A, p-value = 0.003998					

Table 3B. 28: Children from the Traveller community

	Very Early	Early	About the Right Time	Late	Very Late	Don't know	Refused	n
Total (n)	28	64	93	51	12	11	6	265
Overall (%)	10.6	24.1	35.1	19.2	4.5	4.2	2.3	
NI (%)	5.0	25.0	35.0	25.0	0.0	7.5	2.5	40
ROI (%)	11.6	24.0	35.1	18.2	5.3	3.6	2.2	225
Total (n)	28	64	91	50	12	9	4	258
Overall (%)	10.8	24.8	35.3	19.4	4.6	3.5	1.6	
GP (%)	17.4	40.7	33.7	5.8	1.2	1.2	0.0	86
Hospital Staff (%)	5.4	23.6	38.2	18.2	3.6	7.3	3.6	55
Other (%)	8.6	13.7	35.0	29.9	7.7	3.4	1.7	117
Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 46.4068, df = N/A, p-value = 0.0004998								

Table 3B. 29: Women from the Traveller community for antenatal care

	Very Early	Early	About the Right Time	Late	Very Late	Don't know	Refused	n
Total (n)	11	20	72	37	13	12	11	176
Overall (%)	6.3	11.4	41.0	21.0	7.4	6.8	6.2	
NI (%)	9.1	4.5	45.5	13.6	4.5	18.2	4.5	22
ROI (%)	5.8	12.3	40.3	22.1	7.8	5.2	6.5	154
Pearson's Chi-squared test χ^2 = 7.2863, df = 6, p-value = 0.2952			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 7.2863, df = N/A, p-value = 0.2964					
Total (n)	11	20	72	34	12	10	9	169
Overall %	6.5	11.8	42.6	20.1	7.1	5.9	5.3	
GP (%)	7.1	15.5	58.3	14.3	2.4	2.4	0.0	84
Hospital Staff (%)	2.9	8.6	31.4	25.7	2.9	14.3	14.3	35
Other (%)	8.0	8.0	24.0	26.0	20.0	6.0	8.0	50
Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 45.9385, df = N/A, p-value = 0.0004998								

There are striking differences between the 3 Traveller demographic groupings in the timing of their presentation of care, with men reported as especially likely to present late and children most likely to be early or on time. There is no significant difference in this pattern according to jurisdiction. GPs were significantly more likely to think children presented early or on time, whereas both hospital and other staff categories were significantly more likely to think women present late than GPs. Again, this may reflect the different ways in which services are used and the sequence of referrals.

Section D: Health Status

Respondents were asked to rate in importance factors having an impact on Traveller health. This of course, represents a purely external view of the determinants of Traveller health, but it is of interest to see what Service Providers think affects Traveller health. A clear majority, in both jurisdictions, considered all these wider determinants as of some importance.

Table 3B. 30: Socio-economic factors

	Not at all important	Somewhat important	Neither important nor unimportant	Important	Very important	Don't know	Refused	n
Total (n)	7	11	37	97	182	17	5	356
Overall (%)	2.0	3.1	10.4	27.2	51.1	4.8	1.4	
NI (%)	2.1	8.3	10.4	25.0	47.9	4.2	2.1	48
ROI (%)	1.9	2.3	10.4	27.6	51.6	4.9	1.3	308
Total (n)	7	11	37	95	178	15	5	348
Overall (%)	2.0	3.2	10.7	27.3	51.1	4.3	1.4	
GP (%)	1.1	3.4	17.1	33.0	42.0	2.3	1.1	88
Hospital Staff (%)	2.6	0.0	6.5	41.6	39.0	7.8	2.6	77
Other (%)	2.2	4.4	9.3	18.6	60.7	3.8	1.1	183

A clear majority (78.3%) of respondents considered socio-economic factors as either important or very important to Traveller health. Socio-economic factors were considered as either important or very important in both jurisdictions (72.9% in NI and 79.2% in ROI). Whilst a large majority of all professional groupings similarly agreed, the Other grouping was clearly the most likely to consider such factors very important (60.7%).

Table 3B. 31: Cultural ways

	Not at all important	Somewhat important	Neither important nor unimportant	Important	Very important	Don't know	Refused	n
Total (n)	1	10	31	137	160	13	4	356
Overall (%)	0.3	2.8	8.7	38.5	45.0	3.6	1.1	
NI (%)	0.0	4.2	12.5	37.5	41.7	4.2	0.0	48
ROI (%)	0.3	2.6	8.1	38.6	45.5	3.6	1.3	308
Total (n)	1	10	31	135	156	11	4	348
Overall (%)	0.3	2.9	8.9	38.8	44.8	3.2	1.1	
GP (%)	1.1	5.7	8.0	42.0	40.9	1.1	1.1	88
Hospital Staff (%)	0.0	0.0	5.2	42.9	44.2	6.5	1.3	77
Other (%)	0.0	2.7	10.9	35.5	47.0	2.7	1.1	183

Cultural factors similarly were clearly rated as important (83.5%) by respondents overall. Just 1 respondent in the entire survey thought culture not at all important. A clear majority of respondents in both jurisdictions (79.2% NI and 84.1% ROI) and across professional groupings thought culture important or very important, not significantly different in any category.

Table 3B. 32: Environmental conditions

	Not at all important	Somewhat important	Neither important nor unimportant	Important	Very important	Don't know	Refused	n
Total (n)	2	8	41	117	173	11	4	356
Overall (%)	0.6	2.4	11.5	32.9	48.6	3.2	1.1	
NI (%)	2.1	6.3	10.4	31.3	45.8	4.2	0.0	48
ROI (%)	0.3	1.6	11.7	33.1	49.0	2.9	1.3	308
Total (n)	2	8	41	115	169	9	4	348
Overall (%)	0.6	2.3	11.8	33.0	48.6	2.6	1.1	
GP (%)	0.0	2.3	15.9	51.1	29.5	0.0	1.1	88
Hospital Staff (%)	0.0	1.3	13.0	27.3	49.3	7.8	1.3	77
Other (%)	1.1	2.7	9.3	26.8	57.4	1.6	1.1	183
Pearson's Chi-squared test $\chi^2 = 36.7794$, df = 12, p-value = 0.0002426			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 36.7794$, df = N/A, p-value = 0.0009995					

Environmental conditions were again rated as either important (32.9%) or very important (48.6%) by a large majority of respondents overall. A clear majority agreed in both jurisdictions (77.1% NI and 82.1% ROI). Similarly most respondents in each of the 3 professional groupings rated environmental conditions as important, though again there was a highly significant difference between the categories, with GPs least likely of the three groups to rate this factor as very important (29.5%) though a majority rated it as important (51.1%).

Table 3B. 33: Social and community networks

	Not at all important	Somewhat important	Neither important nor unimportant	Important	Very important	Don't know	Refused	n
Total (n)	1	11	50	149	120	21	4	356
Overall (%)	0.3	3.1	14.0	41.8	33.7	5.9	1.1	
NI (%)	0.0	4.2	12.5	37.5	39.6	6.3	0.0	48
ROI (%)	0.3	2.9	14.3	42.5	32.8	5.8	1.3	308
Total (n)	1	11	50	147	116	19	4	348
Overall (%)	0.3	3.2	14.4	42.2	33.3	5.4	1.1	
GP (%)	0.0	3.4	20.5	54.6	15.9	4.6	1.1	88
Hospital Staff (%)	0.0	1.3	10.4	39.0	37.7	10.4	1.3	77
Other (%)	0.6	3.8	13.1	37.7	40.0	3.8	1.1	183
Pearson's Chi-squared test $\chi^2 = 24.8646$, df = 12, p-value = 0.01548			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 24.8646$, df = N/A, p-value = 0.007996					

Social and community networks were also rated as important (41.8%) or very important (33.7%) by a large majority of respondents overall. Again also, as with the other determinants, the three health professional groupings rated their importance highly, but GPs were once more significantly less likely to rate networks as very important (15.9%) compared to the other two groups.

Table 3B. 34: Individual lifestyle factors

	Not at all important	Somewhat important	Neither important nor unimportant	Important	Very important	Don't know	Refused	n
Total (n)	1	12	41	138	146	12	5	356
Overall (%)	0.3	3.4	11.5	38.7	41.0	3.4	1.4	
NI (%)	0.0	4.2	16.7	41.7	33.3	4.2	0.0	48
ROI (%)	0.3	3.3	10.7	38.3	42.2	3.6	1.6	308
Total (n)	1	12	41	137	141	11	5	348
Overall (%)	0.3	3.4	11.8	39.4	40.5	3.2	1.4	
GP (%)	0.0	6.8	11.4	51.1	28.4	1.1	1.1	88
Hospital Staff (%)	1.3	0.0	9.1	40.3	40.3	7.8	1.3	77
Other (%)	0.0	3.3	13.1	33.3	46.5	2.2	1.6	183
Pearson's Chi-squared test $\chi^2 = 26.463$, df = 12, p-value = 0.009225			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 26.463$, df = N/A, p-value = 0.005997					

Individual lifestyle factors were rated as important (38.7%) or very important (41.0%) by a similarly large majority, again not significantly different according to jurisdiction, but with GPs more likely to rate lifestyle as important (51.1%) rather than very important (28.4%) compared to the other two professional categories.

Table 3B. 35: Access to services

	Not at all important	Somewhat important	Neither important nor unimportant	Important	Very important	Don't know	Refused	n
Total (n)	2	19	60	139	121	11	4	356
Overall (%)	0.6	5.3	16.8	39.0	34.0	3.1	1.1	
NI (%)	0.0	10.4	16.7	33.3	33.3	6.3	0.0	48
ROI (%)	0.7	4.6	16.9	39.9	34.1	2.6	1.3	308
Total (n)	2	19	60	137	117	9	4	348
Overall (%)	0.6	5.4	17.2	39.4	33.6	2.6	1.1	
GP (%)	1.1	11.4	27.3	43.2	14.8	1.1	1.1	88
Hospital Staff (%)	0.0	3.9	15.6	39.0	33.8	6.5	1.3	77
Other (%)	0.6	3.3	13.1	37.7	42.6	1.6	1.1	183
Pearson's Chi-squared test $\chi^2 = 35.6337$, df = 12, p-value = 0.0003710			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 35.6337$, df = N/A, p-value = 0.0004998					

Finally, in this section, respondents were asked to rate access to services in importance as a health determinant. This was rated also as important (39.0%) or very important (34.0%) by a majority of respondents, with no significant difference according to jurisdiction. A majority of all 3 professional groupings rated this as important or very important also, but again the GPs differed from the other 2 groups in being statistically least likely to rate this factor as very important (14.8%). The rating of the importance of this factor was a little lower than the others, possibly suggesting that service providers see access as somewhat less important than some of the other determinants.

Figure 1: What things impact most on the health of the Traveller community?

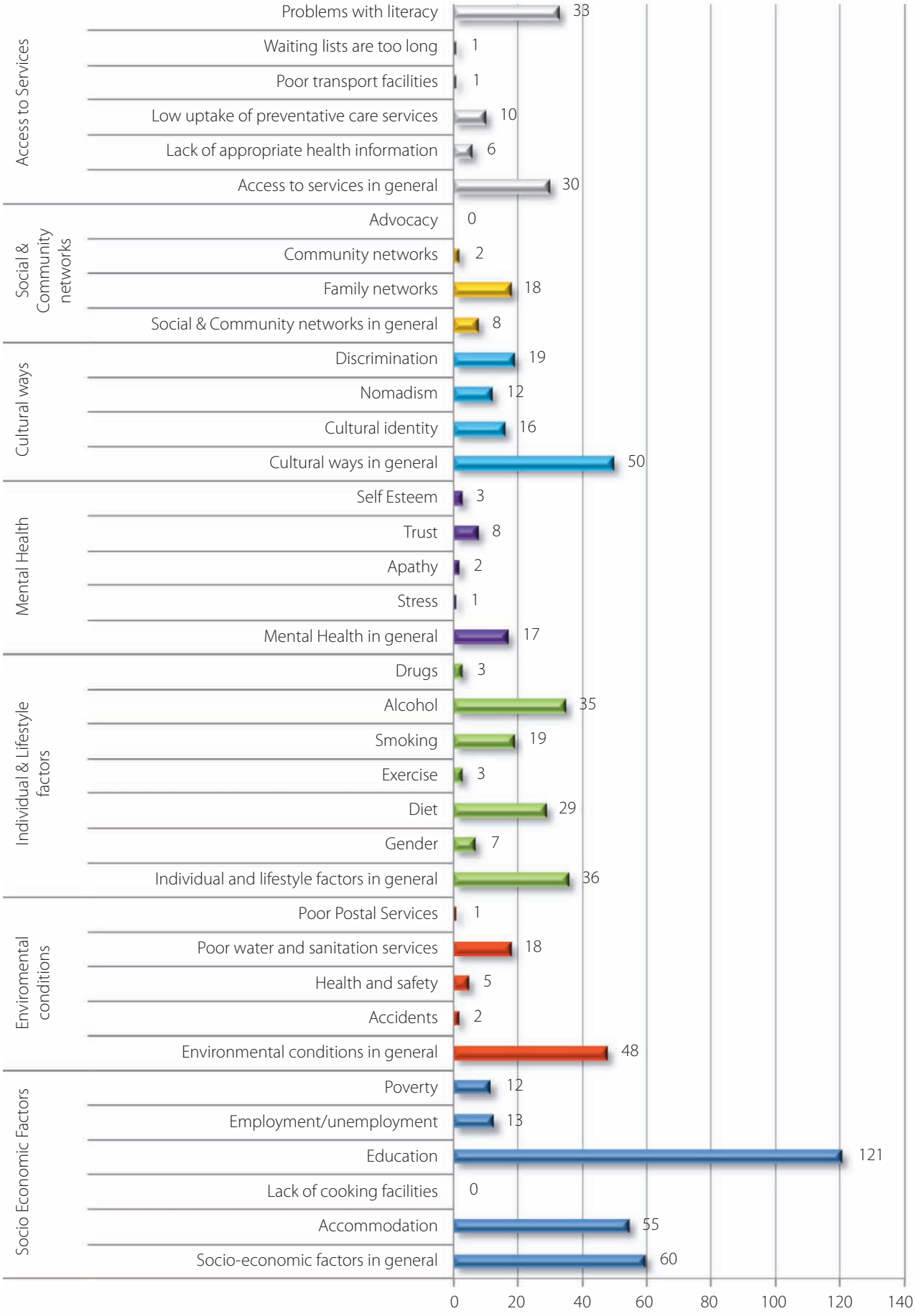


Figure 1 gives the response to an open question in which respondents were asked to list the three factors they considered made the most impact on the health of the Traveller community. The question was put first unprompted and then if necessary prompted from a list of factors in 7 categories. Accordingly respondents could make their own open suggestions or give their reaction to a preset list. Frequency of mention is presented in the figure. This shows that education was clearly in front of any other determinant as a cited factor, followed by socio-economic factors in general, accommodation adequacy and cultural factors. Notably lifestyle factors, including smoking, alcohol and drugs did not rate very high mention. Of other comments spontaneously made, violence, particularly against women was highlighted.

Section E: Interface Between Travellers and Your Service

Overall respondents reported significant difficulties for Travellers in using their services. There were marked difficulties with understanding instructions and understanding the nature and cause of their illness. Respondents felt that Travellers had less difficulty with asking questions and understanding the language used in the responses to these. It was not felt to be difficult to establish a relationship of trust with most of their Traveller clients.

In this section, respondents were asked in general, to what extent their Traveller patients found the following interactions easy or difficult:

Table 3B. 36: Understand instructions about treatments

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	6	44	125	128	14	11	2	330
Overall (%)	1.8	13.3	37.9	38.8	4.2	3.2	0.6	
NI (%)	2.2	8.9	24.4	48.9	8.9	6.7	0.0	45
ROI (%)	1.8	14.0	40.0	37.2	3.5	2.8	0.7	285
Total (n)	6	44	124	125	14	9	1	323
Overall (%)	1.9	13.6	38.4	38.7	4.3	2.8	0.3	
GP (%)	0.0	21.6	40.9	31.8	4.6	1.1	0.0	88
Hospital Staff (%)	1.4	10.8	41.9	39.2	4.1	2.7	0.0	74
Other (%)	3.1	10.6	35.4	42.2	4.4	3.7	0.6	161

Respondents gave a range of responses when asked how easy or difficult it was for Travellers to understand instructions about treatments. Opinion was divided, mainly being rated as neither easy nor difficult (37.9%) or as difficult (38.8%). There was no significant difference in response according to jurisdiction or professional grouping.

Table 3B. 37: Understand the nature and cause of their illness

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	3	26	102	161	17	10	1	320
Overall (%)	0.9	8.0	31.6	49.8	5.3	3.1	0.3	
NI (%)	2.3	6.8	34.1	45.5	6.8	4.6	0.0	44
ROI (%)	0.7	8.3	31.5	51.1	5.1	2.9	0.4	276
Total (n)	3	26	101	158	17	8	0	313
Overall (%)	1.0	8.3	32.3	48.9	5.3	2.5	0.0	
GP (%)	0.0	9.1	28.4	58.0	3.4	1.1	0.0	88
Hospital Staff (%)	1.3	6.8	37.8	46.0	4.1	4.1	0.0	74
Other (%)	1.3	8.6	31.8	48.3	7.3	2.6	0.0	151

Asked if Travellers generally understood the nature and cause of their illness, a third (31.6%) thought it neither easy nor difficult but almost half (49.8%) thought it difficult for Travellers. Again there was no significant difference by jurisdiction or professional grouping and the tendency therefore was to rate this as difficult for Travellers.

Table 3B. 38: Understand factors concerning their health and wellbeing

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	7	31	118	144	22	11	2	335
Overall (%)	2.1	9.3	35.2	43.0	6.6	3.3	0.6	
NI (%)	2.1	10.6	38.3	36.2	6.4	4.3	2.1	47
ROI (%)	2.1	9.0	34.7	44.1	6.6	3.1	0.4	288
Total (n)	7	31	116	141	22	9	1	327
Overall (%)	2.1	25.2	35.5	43.1	6.7	2.7	0.3	
GP (%)	2.3	4.5	34.1	53.4	5.7	0.0	0.0	88
Hospital Staff (%)	1.3	2.7	36.0	46.7	6.7	5.3	1.3	75
Other (%)	2.4	15.2	36.0	36.0	7.3	3.0	0.0	164
Pearson's Chi-squared test $\chi^2 = 24.2474$, df = 12, p-value = 0.01882								

There was again a range of opinion on whether Travellers understand factors concerning their health and wellbeing. A majority of respondents thought it either difficult (43.0%) or very difficult (6.6%) for Travellers. GPs were the professional grouping who thought this most problematic, rating it as either difficult (53.4%) or very difficult (5.7%).

Table 3B. 39: Understand the vocabulary you use

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	12	87	119	95	26	8	2	349
Overall (%)	3.4	25.0	34.1	27.2	7.4	2.3	0.6	
NI (%)	4.2	14.6	31.3	33.3	10.4	4.2	2.1	48
ROI (%)	3.3	26.6	34.6	26.3	7.0	2.0	0.3	301
Pearson's Chi-squared test $\chi^2 = 7.0972$, df = 6, p-value = 0.3120			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 7.0972$, df = N/A, p-value = 0.2764					
Total (n)	12	86	117	93	26	6	1	341
Overall %	3.5	25.3	34.3	2.7	7.6	1.7	0.3	
GP (%)	5.7	25.0	43.2	20.5	4.6	1.1	0.0	88
Hospital Staff (%)	4.0	23.7	32.9	25.0	7.9	5.3	1.3	76
Other (%)	2.3	26.0	30.5	31.6	9.0	0.6	0.0	177
Pearson's Chi-squared test $\chi^2 = 19.7955$, df = 12, p-value = 0.07105			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 19.7955$, df = N/A, p-value = 0.05347					

There was also a range of opinion on whether Travellers understand the vocabulary health professionals use, reflecting perhaps the range and complexity of situations in which Travellers engage with services. It was seen as neither easy nor difficult by just over a third of respondents (34.1%) but with similar numbers either side of this estimate rating it as either easy (25.0%) or difficult (27.2%). There was a difference of borderline statistical significance among the Professional groups with GPs most likely to state that it was neither easy nor difficult (43.2% compared to 32.9% of hospital professionals and 30.5% of the other category).

Table 3B. 40: Carry out written instruction (for example, with information leaflets or prescriptions)

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	4	14	50	161	90	15	4	341
Overall (%)	1.2	4.1	14.7	47.2	26.4	4.4	1.2	
NI (%)	0.0	0.0	20.8	45.8	25.0	6.2	2.1	48
ROI (%)	1.4	5.8	13.7	47.4	26.6	4.1	1.0	293
Total (n)	4	17	50	156	90	13	3	333
Overall (%)	1.2	5.1	15.0	46.8	27.0	3.9	0.9	
GP (%)	1.2	3.5	17.4	51.2	20.9	5.8	0.0	86
Hospital Staff (%)	1.3	5.3	16.0	46.7	20.0	6.7	4.0	75
Other (%)	1.2	5.8	13.4	44.8	33.1	1.7	0.0	172
Pearson's Chi-squared test $\chi^2 = 21.4035$, df = 12, p-value = 0.04477			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 21.4035$, df = N/A, p-value = 0.03848					

Asked how easy it was for Travellers to carry out written instructions, for example with information leaflets or prescriptions, most respondents rated this as either difficult (47.2%) or very difficult (26.4%). There was no difference in response according to jurisdiction. However there was a significant variation according to professional grouping, the Other Professionals category being most likely to rate this as very difficult for Travellers (33.1%, compared with 20.9% of GPs and 20.0% of hospital staff).

Table 3B. 41: Ask questions about their condition

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	20	87	101	97	17	10	2	334
Overall (%)	6.0	26.0	30.2	29.0	5.1	3.0	0.6	
NI (%)	8.5	23.4	36.2	19.2	6.4	4.3	2.1	47
ROI (%)	5.6	26.5	29.3	30.7	4.9	2.8	0.4	287
Total (n)	20	85	100	95	17	8	1	326
Overall (%)	6.1	26.1	30.7	29.1	5.2	2.4	0.3	
GP (%)	5.7	28.4	31.8	31.8	2.3	0.0	0.0	88
Hospital Staff (%)	7.9	26.3	30.3	22.4	6.6	5.3	1.3	76
Other (%)	5.6	24.7	30.2	30.9	6.2	2.5	0.0	162

There was again a spectrum of opinion on whether it was easy for Travellers to ask about their condition, from very easy through to very difficult. A third thought it neither easy nor difficult (30.2%), flanked either side by those who thought it either easy (26.0%) or difficult (29.0%). There was no difference in pattern according to jurisdiction or professional grouping.

Table 3B. 42: Ask questions pertaining to the consultation/treatment event

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	17	90	103	96	12	8	3	329
Overall (%)	5.2	27.3	31.3	29.2	3.6	2.4	0.9	
NI (%)	4.4	30.4	32.6	21.7	4.4	4.4	2.2	46
ROI (%)	5.3	26.9	31.1	30.4	3.5	2.1	0.7	283
Total (n)	17	89	101	95	11	6	2	321
Overall (%)	5.3	27.7	31.4	29.6	3.4	1.9	0.6	
GP (%)	5.7	30.7	34.1	28.4	1.1	0.0	0.0	88
Hospital Staff (%)	6.7	34.7	24.0	24.0	5.3	4.0	1.3	75
Other (%)	4.4	22.8	33.5	32.9	3.8	1.9	0.6	158

Asked more specifically how easy it was to ask questions about the consultation or treatment event, there was again a wide spectrum of response, with no difference according to jurisdiction or professional grouping. Relatively few respondents rated it as very difficult (3.6%), however.

Table 3B. 43: How easy or difficult do you find it to establish a relationship of trust with your Traveller patients?

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know	Refused	n
Total (n)	20	108	100	52	14	29	30	353
Overall (%)	5.7	30.6	28.3	14.7	4.0	8.2	8.5	
NI (%)	2.1	29.2	31.2	12.5	6.2	12.5	6.2	48
ROI (%)	6.2	30.8	27.9	15.1	3.6	7.5	8.8	305
Total (n)	20	108	99	52	14	27	25	345
Overall %	5.8	31.3	28.7	15.1	4.1	7.8	7.2	
GP (%)	6.8	39.8	28.4	14.8	3.4	1.1	5.7	88
Hospital Staff (%)	6.5	39.0	26.0	9.1	3.9	5.2	10.4	77
Other (%)	5.0	23.9	30.0	17.8	4.4	12.2	6.7	180
Pearson's Chi-squared test $\chi^2 = 21.8064$, df = 12, p-value = 0.03975			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 21.8064$, df = N/A, p-value = 0.03948					

Respondents were asked how easy or difficult is was to establish a relationship of trust with their Traveller patients. There was again a range of opinion but the majority found it either easy (30.6%), or neither easy nor difficult (28.3%). Relatively few found it very difficult (4.0%). There was a significant difference according to professional grouping, in that hospital respondents were least likely rate this as difficult (9.1%) but had the highest refusal rate for this question (10.4%). GPs had lower rates of 'don't know' or refusal to answer this question than the other 2 groups.

Section F: Provision of Services to Travellers

Table 3B. 44: Do you conduct domiciliary visits?

Yes	No	N/A
172	164	20

Respondents were asked if they conducted domiciliary visits and 51.2% of those to whom it was applicable said yes.

Table 3B. 45: Is information on how to use your service translated into a format that can be easily understood by Travellers (e.g. posters)?

	Yes	No	Don't know	Refused	n
Total (n)	172	164	10	5	351
Overall (%)	49.0	46.7	2.8	1.4	
NI (%)	52.2	47.8	0.0	0.0	46
ROI (%)	48.5	46.6	3.3	1.6	305
Total (n)	169	161	10	5	345
Overall (%)	49.0	46.7	2.9	1.4	
GP (%)	51.1	45.5	3.4	0.0	88
Hospital Staff (%)	44.0	46.7	2.7	6.7	75
Other (%)	50.0	47.2	2.8	0.0	182
Pearson's Chi-squared test $\chi^2 = 18.6504$, df = 6, p-value = 0.004797	Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 18.6504$, df = N/A, p-value = 0.005497				

Respondents were about equally divided, yes (49.0%) or no (46.7%), on whether information on how to use their service was translated into a format that can be easily understood by Travellers, with no difference according to jurisdiction. There was a significant difference in response according to professional grouping, in that hospital respondents were least likely to answer yes to this question (44.0%) and more likely to refuse (6.7%).

Table 3B. 46: Is information on how to use your service disseminated in a way that ensures Travellers receive it (e.g. information sessions)?

	Yes	No	Don't know	Refused	n
Total (n)	174	159	14	4	351
Overall (%)	49.6	45.3	4.0	1.1	
NI (%)	41.3	52.2	6.5	0.0	46
ROI (%)	50.8	44.3	3.6	1.3	305
Total (n)	172	155	14	4	345
Overall (%)	49.9	45.0	4.0	1.2	
GP (%)	46.6	52.3	1.1	0.0	88
Hospital Staff (%)	37.3	50.7	9.3	2.7	75
Other (%)	56.6	39.0	3.3	1.1	182
Pearson's Chi-squared test $\chi^2 = 16.9791$, df = 6, p-value = 0.00936	Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi 2 = 16.9791$, df = N/A, p-value = 0.007996				

Again, asked if information on how to use their service was disseminated in a way that ensures Travellers receive it, such as information sessions, respondents were about equally divided, yes (49.6%) and no (45.3%) and there was no difference according to jurisdiction. Hospital staff again differed significantly in their response, being least likely to say yes (37.3%) and most likely not to know (9.3%).

Table 3B. 47: In the course of your usual practice, is there engagement with Traveller Advocates to help support service delivery?

	Yes	No	Don't know	Refused	n
Total (n)	204	136	10	1	351
Overall (%)	58.1	38.7	2.8	0.3	
NI (%)	50.0	47.8	2.2	0.0	46
ROI (%)	59.3	37.4	3.0	0.3	305
Total (n)	200	134	10	1	345
Overall (%)	58.0	38.8	2.9	0.3	
GP (%)	39.8	60.2	0.0	0.0	88
Hospital Staff (%)	41.3	46.7	10.7	1.3	75
Other (%)	73.6	25.3	1.1	0.0	182
Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi 2 = 60.2705$, df = N/A, p-value = 0.0004998					

Respondents were asked whether in the course of their usual practice, there was engagement with Traveller advocates to help support service delivery. Half (50.0%) in NI and over half (59.3%) in ROI said yes. There was a highly significant difference according to professional grouping. The Other Professional category being much more likely (73.6%) to report such engagement than GPs (39.8%) or hospital staff (41.3%).

Table 3B. 48: Have you ever received Traveller Cultural Awareness training?

	Yes	No	Don't know	Refused	n
Total (n)	157	192	1	1	351
Overall (%)	44.7	54.7	0.3	0.3	
NI (%)	41.3	58.7	0.0	0.0	46
ROI (%)	45.3	54.1	0.3	0.3	305
Total (n)	153	190	1	1	345
Overall (%)	44.3	55.1	0.3	0.3	
GP (%)	18.2	81.8	0.0	0.0	88
Hospital Staff (%)	34.7	62.7	1.3	1.3	75
Other (%)	61.0	39.0	0.0	0.0	182
Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) $\chi^2 = 54.4767$, df = N/A, p-value = 0.0004998					

A majority of respondents (54.7%) said they had never received cultural awareness training. There was no difference according to jurisdiction in response to the question. However, there was a marked difference according to professional grouping, 61% of the other professional category said yes, followed by 34.7% of hospital staff and just 18.2% of GPs.

Table 3B. 49: How helpful was this training?

	Very unhelpful	Unhelpful	Neither helpful nor unhelpful	Helpful	Very helpful	Don't know	Refused	n
Total (n)	2	4	28	62	59	1	1	157
Overall (%)	1.3	2.5	17.8	39.4	37.6	0.6	0.6	
NI (%)	5.3	0.0	10.5	31.6	52.6	0.0	0.0	19
ROI (%)	0.7	2.9	18.8	40.6	35.5	0.7	0.7	138
Total (n)	1	4	28	60	58	1	1	153
Overall (%)	0.6	2.6	18.3	39.2	38.0	0.6	0.6	
GP (%)	0.0	0.0	25.0	43.8	31.2	0.0	0.0	16
Hospital Staff (%)	0.0	0.0	15.4	50.0	34.6	0.0	0.0	26
Other (%)	0.9	3.6	18.0	36.0	39.6	0.9	0.9	111

A majority of respondents who had received such training found it either helpful (39.4%) or very helpful (37.6%), with no significant difference according to jurisdiction or professional grouping.

Table 3B. 50: Do you think having an ethnic identifier is helpful to Health Service Providers when providing services to Travellers?

	Yes	No	Don't know	Refused	n
Total (n)	189	102	57	3	351
Overall (%)	53.8	29.0	16.2	0.9	
NI (%)	78.3	17.4	2.2	2.2	46
ROI (%)	50.2	30.7	18.4	0.7	305
Pearson's Chi-squared test χ^2 = 15.8676, df = 3, p-value = 0.001207	Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 15.8676, df = N/A, p-value = 0.002999				
Total (n)	183	102	57	3	345
Overall (%)	53.0	29.6	16.5	0.9	
GP (%)	30.7	48.9	19.3	1.1	88
Hospital Staff (%)	48.0	29.3	21.3	1.3	75
Other (%)	65.9	20.3	13.2	0.6	182
Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 33.8588, df = N/A, p-value = 0.0004998					

A majority of respondents (53.8%) agreed that an ethic identifier is helpful. There was a highly significant difference according to jurisdiction. A clear majority in NI, where there is an ethnic identifier used by some providers, agreed (78.3%), whereas respondents in ROI were more divided, just half said yes (50.2%) and around a fifth (18.4%) did not know. There was also a significant difference according to professional grouping to this question, with GPs (30.7%) least likely and the other category most likely to agree (65.9%) and hospital staff in the middle (48.0%).

Table 3B. 51: How often do you think that Travellers experience discrimination in their use of health services in general?

	Never	Rarely	Sometimes	Often	Very Often	Don't know	Refused	n
Total (n)	21	65	140	57	36	28	2	349
Overall (%)	6.0	18.6	40.1	16.3	10.3	8.0	0.6	
NI (%)	2.2	19.6	47.8	10.9	13.0	6.5	0.0	46
ROI (%)	6.6	18.5	38.9	17.2	9.9	8.3	0.7	303
Total (n)	21	65	134	57	36	28	2	343
Overall %	6.1	18.9	39.0	16.6	10.5	8.2	0.6	
GP (%)	6.8	22.7	38.6	19.3	6.8	5.7	0.0	88
Hospital Staff (%)	8.0	18.7	36.0	17.3	12.0	6.7	1.3	75
Other (%)	5.0	17.2	40.6	15.0	11.7	10.0	0.6	180

Respondents were asked two questions about discrimination. Firstly, they were asked how often they thought Travellers experience discrimination in their use of health services in general. While there was a wide range of responses to this question most respondents (66.7%) agreed either that it sometimes occurred (40.1%), or more often than that (26.6%). There was no significant difference of opinion on this according to jurisdiction or professional grouping.

Table 3B. 52: How often do you think Travellers experience discrimination in their use of the type of service you provide?

	Never	Rarely	Sometimes	Often	Very Often	Don't know	Refused	n
Total (n)	121	118	74	19	3	9	3	347
Overall (%)	34.9	34.0	21.3	5.5	0.9	2.6	0.9	
NI (%)	50.0	26.1	6.5	10.9	2.2	4.4	0.0	46
ROI (%)	32.6	35.2	23.6	4.7	0.7	2.3	1.0	301
Pearson's Chi-squared test χ^2 14.8659, df = 6, p-value = 0.02133			Pearson's Chi-squared test with simulated p-value (based on 2000 replicates) χ^2 = 14.8659, df = N/A, p-value = 0.03048					
Total (n)	120	114	73	19	3	9	3	341
Overall (%)	35.1	33.4	21.4	5.6	0.9	2.6	0.9	
GP (%)	39.5	34.9	18.6	5.8	0.0	0.0	1.2	86
Hospital Staff (%)	32.4	28.4	20.3	10.8	1.4	5.4	1.4	74
Other (%)	34.3	34.8	23.2	3.3	1.1	2.8	0.6	181

When asked how often they thought Travellers experience discrimination in the use of the type of service respondents they themselves provided, the pattern was somewhat different in that some people still indicated they thought discrimination sometimes or more frequently than that occurred (27.7%), but considerably less frequently than in general. There was a significant difference according to jurisdiction, half (50.0%) in NI saying it never occurred but just over a third (32.6%) in ROI saying never. There was no significant difference according to professional grouping on this question.

Figure 2: What things would most improve the health and wellbeing for the Traveller community?

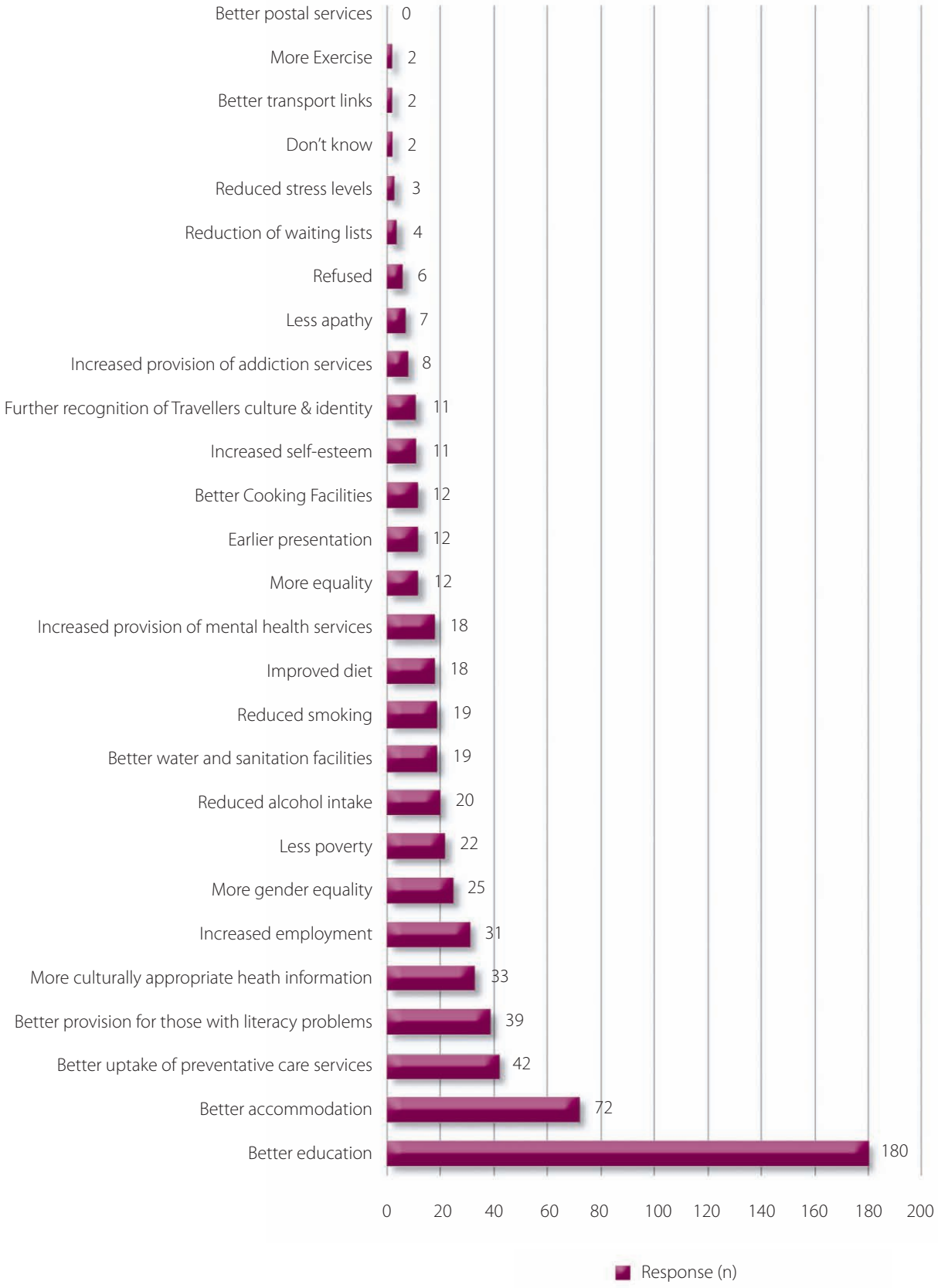
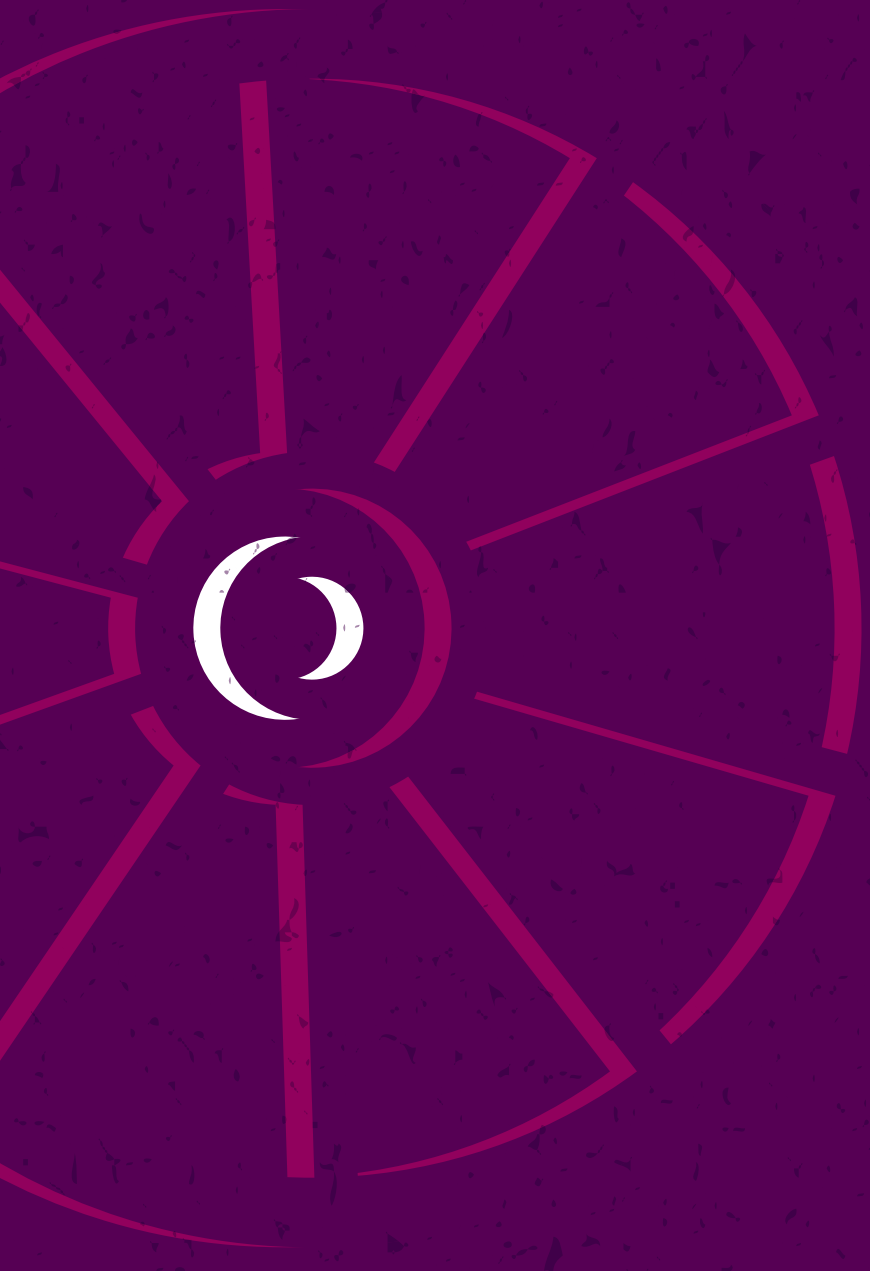


Figure 2 again presents the response to an open-ended question on what 3 factors would most improve the health and wellbeing of the Traveller community, the format being both unprompted and then as necessary, prompted. Frequency of mention is presented in rank order. Again, better education was ranked by far the most highly, followed by better accommodation, better uptake of preventive services, better provision for those with literacy problems and more culturally appropriate services.

DISCUSSION



DISCUSSION

This Service Providers survey gives valuable insight into aspects of the current service delivery for Travellers and complements information gathered from other parts of the study. Respondents were selected in a purposeful manner but do represent a diversity of practice across all the main services and a spectrum of experience. We sampled in this way, as opposed, for example, to a bi-national random sample, because Traveller populations are concentrated in particular areas and many health professionals do not have much practical experience of care delivery to Travellers. Whilst as a consequence very few reported no Traveller engagement at all, and this was the principal reason given also for non-participation of those others we contacted, those interviewed extend from people with daily engagement with Travellers to those who see them less commonly.

This is agreement by Service Providers on many of the points Travellers themselves raised as problems, such as literacy, difficulty in following prescribed instructions, understanding of the consultation and the clinical implications of the encounter. These are well established points and are reinforced here. There are notably few differences according to jurisdiction suggesting a fairly typical reality, even though with the caveat that respondent numbers in NI are relatively small.

There is quite a lot of supportive evidence that suggests Service Providers, particularly those actually dealing with Travellers, do understand some of the dilemmas and barriers Travellers face and are willing to engage with addressing these. Travellers and Traveller advocates appear to have achieved quite a level of recognition on a number of issues. For instance, the majority of Service Providers do show an understanding of the wider health determinants and clearly recognise the importance of socio-economic, environmental and cultural factors, as well as individual lifestyle and access issues. They also acknowledge discrimination as a possible factor in service delivery. Education was recognised as critically important by Service Providers, both as a contributory factor for ill-health and the principal means of improving it. These findings in this section of the survey are significant positive considerations to capitalise upon in implementing the findings of All Ireland Traveller Health study as a whole.

Service Providers do agree too that communication and trust are factors of importance in working to provide services for Travellers. Again there is a need for a 2-way process here in triangulating these findings with the other parts of this survey. Trust, dignity and respect were important to Travellers in the census survey and the qualitative accounts amplify the importance of this. The professional, clinical ethos displayed by the service providers in this survey is important, as is quality of engagement. The scientific literature supports the need for cultural training in dealing with minority groupings and service providers seem very positively inclined to support that, on this evidence.

It is of interest that the ethnic identifier finds support in NI, where it is actually in place in some areas already and that there is still ambivalence about this in ROI. This shows the need for consultation and engagement with service providers on the ground if this is to be actually implemented into the future.

There are some notable differences according to professional category that merit comment and further policy exploration. GPs were the hardest group to engage with this survey, particularly in NI. This reflects the fact that they operate in a busy environment, are regularly asked to take part in surveys and many have no Traveller list. We did not have enough of the 'rarely or never' category to explore reasons for this in sufficient depth. However, given that the choice of doctor scheme still operates in ROI it is likely that the reasons given a decade ago in the Task Force Report (Report of the Task Force on the Travelling Community, 1995) are similar and still relevant today. The qualitative consultation corroborates that many of the barriers are practical and operational in nature. GPs were least likely to rate as very important the wider health determinants, least likely to have had engagement with Traveller advocates or awareness training. However, they were more likely to find engagement with Travellers easier than other groupings, reflecting the fact that they provide frontline services and offer care for minor as well as more serious conditions.

The hospital respondents differ in their response to the GPs, again reflecting the nature of care they offer. They are most likely to prescribe medication on a par with other patients, to have encounters that present difficult communication challenges and have little engagement with continuity of care or preventive service issues. The Other Professional category does contain a heterogeneous group of community or management providers, but they have the most appreciation of the issues Traveller advocates wish to see addressed and have had more engagement with those issues.

There are some important demographic concerns raised in this survey that link to findings in the other sections. We see that children are the first priority with Travellers, and women engage earlier than men. The presentation for antenatal and postnatal care continues to be important. Given the mortality findings in the vital statistics sections, particularly for men and in relation to respiratory and cardiovascular disease, it is important also to get earlier and more active engagement, especially in primary care, and to address the need for more engagement by Travellers in preventive services and follow-up, particularly for management of chronic disease, such as for respiratory and cardiovascular conditions. The poor health of male Travellers documented in our other reports, and the perception that they present particularly late for care, suggest need for urgent action to engage with this group of people.

Our
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All Ireland
Traveller
Health Study

DEPARTMENT
OF HEALTH & CHILDREN
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AGUS LEANAÍ

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and Public Safety

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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All Ireland Traveller Health Study

Our Geels

Discussion & Recommendations

All Ireland Traveller Health Study

Discussion & Recommendations
Part C of Technical Report 3

September 2010

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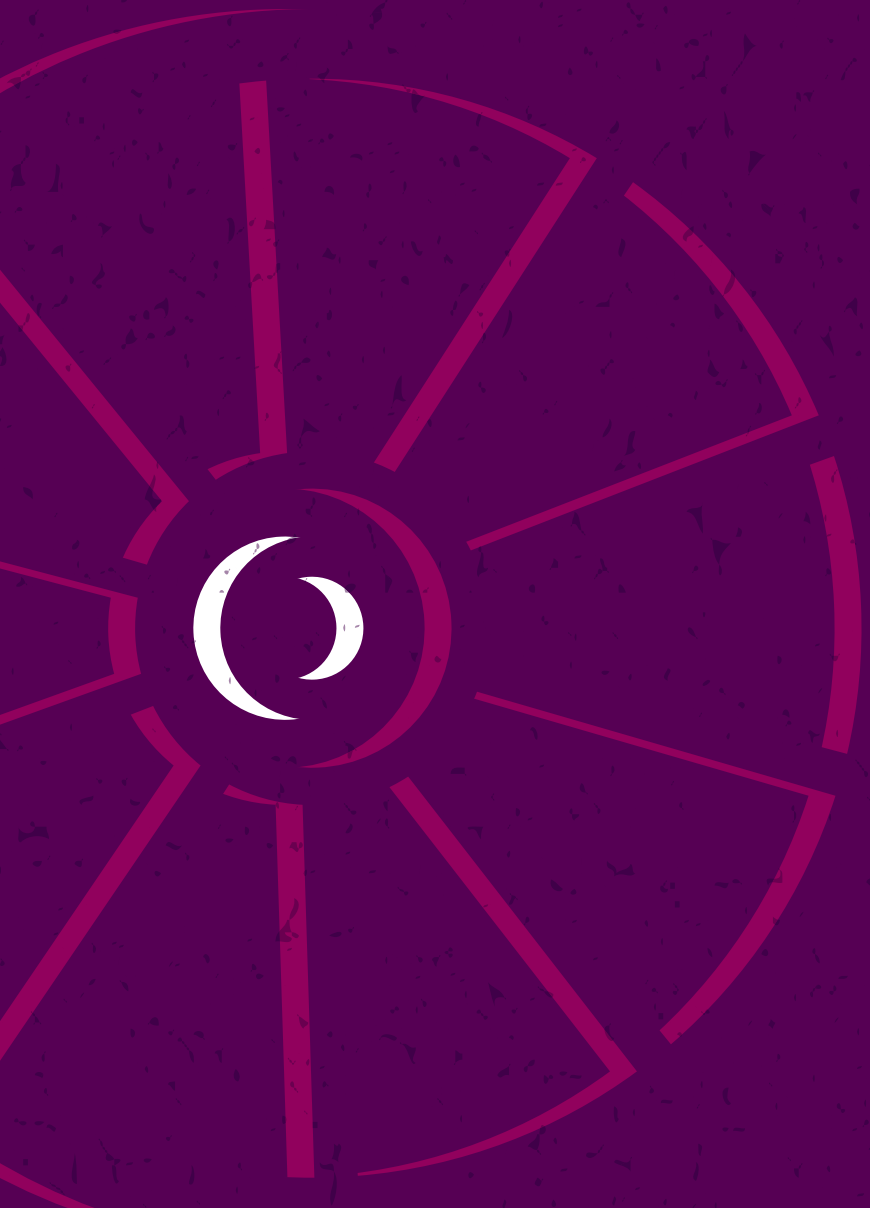
DISCUSSION OF FINDINGS OF ALL 3 TECHNICAL REPORTS



Introduction

This was a complex and ambitious set of studies achieved with unprecedented cooperation and support of the Traveller community itself across the island of Ireland. In this concluding chapter we discuss the principal findings, drawing together the evidence base in all 3 Technical Reports from the census survey, the consultative studies and the associated retrospective mortality study and prospective birth cohort study. The views expressed herein are the independent assessment of the research team who undertook this commission.

While all stakeholders played a valued role we consider the input of Travellers themselves to have been remarkable. The mapping, scoping and training framework put in place to collect the core data was almost certainly indispensable to the novel methodology and in itself illustrates the capabilities and positive characteristics of a community that is not simply marginalised, but often discriminated against in wider society, compounding the material disadvantage that it suffers.

There are high expectations from the stakeholders about the study results, the Government Departments because of the resources invested as a measure of their commitment, the advocacy and representative groups because of a long struggle to achieve status for the Traveller community as a respected and distinct group in society and most importantly the respondents themselves, exemplified by an 80% participation rate in the anchor census survey for this project, which is by any standards an excellent rate for a survey of this depth and unprecedented for this group.

Capitalising on Positive Aspects of Traveller Life to Achieve Much Needed Change

Many positive aspects of Traveller culture and value systems should be better promoted. The strong sense of community, family support, religiosity, and valuing of Traveller culture and identity emerge from the data, complemented by both quantitative and qualitative findings and this should be capitalised upon. Another key factor is how valued children and young people are in the community. There is also a sense of proportion, fairness and optimism in the datasets, particularly the qualitative discussions and clearly there was a high degree of engagement. *This needs to be disseminated to the general public and harnessed as a means of achieving next steps.*

The research team associated with this project was committed from the outset to a study *for, with and by, Travellers*. We sought, as far as scientifically possible, to collect, describe and analyse the data to which we had privileged access in as accurate, systematic and contextually appropriate a manner as possible. We also saw our principal obligation to be as independent as possible so that our findings would be afforded the fair-minded respect our respondents wished for and deserved.

However, there is a constant judgement call in a project of this scale and sensitivity. Should we call the bad news in black and white? Should we emphasise the positives and complexities, in order to break down the pervasive stereotype that exists about Travellers? Should we keep it succinct to engage

policy makers with the action points, or more nuanced to engage the peer review scientific community and give the project the credibility and longevity it deserves? Most importantly of all, how should we feed back the findings to Travellers themselves? If we try to please all of the people, all of the time, we please no one. The classical Aesop's fable of the group helping the donkey to cross the stream comes to mind. *Therefore the team takes the view that we must tell it as it is, in the depth and subtlety it requires.* The Travellers waited 20 long years for this study and its 3 Technical Reports contain a mine of information. This summary report gives the big messages and the genesis for all the nuances required as its findings start to impact on policy.

A Heterogeneous Community in the 21st Century

The demographic profile suggests a still very young population, but with some recent decline in fertility relative to the study in 1987. The pyramidal structure has altered somewhat since then, with relatively fewer children and more middle-aged adults, but it remains more akin to a developing country profile than to the developed country pattern of the general Irish population. Maternal and child health remains greatly important to this community. The qualitative data in particular highlight that the modern Traveller community is in a stage of fluctuation and change. Many challenges need to be met for both men and women at different life stages, based on this consultation. Traditions that have supported Traveller culture for centuries are still apparent and strong, even amongst younger people but, as with wider society, erosion is taking place and this is impacting on the sense of cohesion and community. Factors such as the intrusion of drug culture into the community are increasingly important and need to be tackled. There is evidence of change in traditions and of the relative empowerment of women. This shows in numerous ways, from the data collection process itself with Peer Researchers, through evidence of specialist women's health services in the census survey, the qualitative consultation and the Service Provider survey, all of which point to the engagement of women. However, men engaged with this project too, both as respondents to the survey and in the consultation groups. At initial planning stages it was uncertain whether information about men should be collected directly or by proxy but it became clear during piloting that men were in fact prepared to be directly interviewed and to participate in discussion. The compelling narrative in Technical Report 3a is self-explanatory and need not be reiterated in detail here.

How Valid are the Survey Findings?

A criticism of any survey based on self-report is that it is not reliable and may suffer from respondent recall and bias. In fact there are many encouraging signs of valid and accurate engagement with the methodology. Firstly, as noted above, there was a high response rate and completion of the various survey instruments. Secondly, there was a spectrum of response, reflecting variability across the community. A detailed, subtle profile emerged, of a population skewed towards the materially disadvantaged part of the social spectrum, but with mixed degrees of self-report on various aspects of their lives, and some very positive cultural features. Thirdly, there was strong evidence of triangulation, a scientific term meaning that the different data sources served to reinforce the findings.

To take some examples: respondents were frank on aspects of poor lifestyle such as smoking or alcohol consumption that might attract criticism from the more zealous end of the health promotion spectrum. The census data provide the prevalence rates in the community and the qualitative data explore reasons behind those prevalence rates. There were high rates of reported discrimination, but not by all of the people all of the time, which might have less credibility if universally reported. This speaks to these authors of the authenticity of the data as reported from the individual families involved. Furthermore, the Service Providers, both in Northern Ireland and Republic of Ireland, agreed that discrimination does occur at about the same rate as Travellers reported it. Conversely, some variables such as employment or low educational attainment do demonstrate a so-called ceiling effect, with almost universally high rates in both jurisdictions.

The qualitative transcripts speak not just of personal experience and engagement with the issues from the Traveller perspective, but also many instances of thoughtful reflection on what might motivate the general population to engage more positively with Travellers. A high degree of verbal flair and wit were regularly on display in the qualitative transcripts, as well as candour, characteristics the general Irish population would believe they share in common.

The ascertainment process of the deaths was painstaking; this was described by one Traveller wit as the pursuit of the 'definitely dead'. It is not likely that there was an over-inflation of numbers, indeed some under-ascertainment is possible given the logistical difficulties discussed in Technical Report 2 on death registration. Our mortality rates, if anything, are likely to be conservative. The cross-checking of cases suggests that the recall of diagnosis in some categories was reasonably accurate by family relatives.

Reasons for High Morbidity and Mortality

The health determinants approach suggests that disease specific endpoints need to be understood from a bio-psychosocial perspective that takes a comprehensive account of positive and negative influences (Whitehead, 1987; O'Shea and Kelleher, 2001; Wilkinson and Marmot, 2003; Mackenbach *et al.,* 2008). The findings from the census and vital statistics Technical Reports are very clear. Travellers experience higher mortality than the general population, have benefited very much less considerably from the downturn in mortality in the 2 decades since data were last examined in 1987 and as a consequence the mortality gap has widened. For men in particular the mortality pattern is bleak.

Age-specific mortality rates suggest excess rates at all ages for both Traveller men and women. We also know from the census count, which was as comprehensive as it is possible to be, that there are negligible numbers of Travellers over 50 years of age. This is not explained by migration, is not explained by integration into the general population, and not explained by denial of Traveller identity. The only realistic explanation is of premature death. The qualitative data also support this cultural reality. Many respondents at interview talked of the lack of role models as older adults and of middle aged women being the 'old hags' of the community, that is, both a rarity and old before their time or conversely 'treasures', akin to the value of antiques.

Cause-specific information suggests that amongst younger adults, traumatic causes, including accidents are an important factor, and more recently suicide is a key contributor. Suicide rates of both young men and women are high and in men many fold higher than contemporaries in the general population. In early to late middle-age, the main causes of death are respiratory and cardiovascular diseases. In the census survey, self-reported morbidity was higher than in the general population also for respiratory conditions including chronic bronchitis and for cardiovascular disease. In children, asthma was the most common ailment reported. Travellers certainly report high levels of typical lifestyle risk factors, seen commonly in materially disadvantaged groups, such as smoking, excessive salt and saturated fat intake and physical inactivity. However, they also report higher rates of diagnosed diabetes, and have high rates of risk factors such as hypertension and raised cholesterol; we discuss implications of this further below. The data suggest that a classical life-course explanation could be at play here. In such a model factors such as early childhood disadvantage are aggravated by adverse adult experiences, compounded by economic problems.

There is also an important psychosocial component (Berkman and Kawachi, 2000; Siegrist and Marmot, 2004; Wilkinson, 2005). Those who are less trusting report more CVD risk factors (McGorrian *et al.,* 2010) and it is well understood in the general literature that unhealthy lifestyle choices are not so much a wilful ignoring by people of a paternalistic health promotion message as a signal of a coping strategy in the face of difficult circumstances (Graham, 1987; McLeroy *et al.,* 1988; Lynch *et al.,* 1997). Our current understanding of cardiovascular disease is that it is a product of proximal adverse lifestyle leading to atheroma and clinical disease but influenced also by social patterning of those risk factors and by early adverse childhood circumstances (Yusuf *et al.,* 2004; Rosengren *et al.,* 2004; Barker, 1995). There is even likely to be a survivor effect at play, as those who survive childhood adversity are more likely to develop chronic disease as adults. Travellers fulfil all these criteria and it is very likely that this constellation of circumstances, coupled with a lack of access to preventive services particularly, makes for an explanation of risk.

Mental Health, Suicide and Social Disintegration

The World Health Organisation (WHO) recently declared that mental ill-health is the new global epidemic (World Health Organisation, 2008) and Travellers, on the evidence of this study, are inordinately burdened by this issue. Premature mortality, especially among younger men, reflects the high rates of suicide and accident-related mortality. The qualitative consultation highlights thoughtful discussion on what it means to be a man in Traveller culture and how Travellers engage with each other and with wider society. The disintegration of traditional family structures, the decline of religious certainty and belief are adverse trends, though not as much as in the wider society. A further compounding issue is the traditional problem of finding employment, which is tied in with identity and personal self-esteem in the accounts of Travellers themselves.

The tight-knit community has positive effects, but also negative, in that there is literally little personal space for individuals and strong incentive to take part in group activities that can be damaging. Drinking patterns can aggravate mental health problems also, as binge drinking is associated with

impulsivity and compounds clinical depression (World Health Organisation, 2008). Add to this a chronic problem with bridging to the general world around them and the corrosive daily relations with the general population Travellers themselves describe, and the mix is complete of poor self-esteem and self-efficacy in an unsupportive environment. There are a number of examples of fatalistic thinking in the narratives, particularly in trying to break the cycle of education and employability. There is ample evidence in these data of risk factors for mental ill-health, depression and suicide, whether from the quantitative census, the qualitative consultation or the mortality study.

Overcoming Educational Barriers

Education is well established as a key health determinant in the general scientific literature (Bambra *et al.,* 2010; Rosengren *et al.,* 2010) and emerges from all aspects of this study as a key need. It is not just that Travellers, as outlined in the introduction to Technical Report 1, do not achieve even a full primary school education in sufficient numbers, or that the relevance and appropriateness of that education deserves scrutiny. It lies deeper than that. There is a cross-generational deprivation at play. Parents cannot help with their children's school education. There are no older people with life experience to steer the community and to call on traditional skills and values. Younger people question their elders about the value of education when they see examples of community members who do not succeed in for instance gaining work as a result of having acquired some level of education. Relative to the general population they are falling constantly further behind.

Education is essential in numerous ways, to empower women to take control of their family and reproductive health, to enable all Travellers, especially men, to achieve skills that will earn a living and to equip everyone to engage constructively in determining their role and contribution to society. The levels of education and conventional employment were so low in the census study that they could not function as discriminating variables in any of the analyses we undertook. The levels of attainment to third level training are literally anecdotal in a community of over 40,000 people. The analogy might be if a county town of similar population size had no personnel within its number to teach in schools, run healthcare and community facilities or provide any skill whatever above the level of manual labour. That is not to say manual labour is not valued, quite the contrary, without it no infrastructure would exist and it is essential to society. However functioning societies require heterogeneous skills.

It would appear that the unit of delivery of education is still not satisfactory. Travellers maintain and exert the right to Nomadism and that should not be in dispute in 2010. However, it is a misperception to say that this is the barrier to educational access as in practice based on the census data most Travellers are resident in a single location during conventional school term. Young people need support after hours to study as it is not easy at home. There is a fine line here in ensuring for instance parenting or after-school programmes that work effectively and simultaneously with schooling without imposing a model which is discriminatory in itself by separating out Traveller children from the rest.

There needs to be a means of persuading the parental generation of the need to break a vicious circle now, by supporting educational goals for their children. Children also need to engage and mix with

others on an equal basis. There is a lot in fact that is good about Traveller culture for children. Children report large networks of family and friends and albeit based on information given by proxy, it is likely that younger Traveller children are relatively sheltered in lifestyle experimentation, precisely because they have still strong family networks.

Lifestyle, Empowerment and Health Status

Many Traveller advocates vigorously reject a paradigm that seeks to explain ill-health within the Traveller community in reductionist terms purely as a matter of adverse lifestyle or disadvantaged social circumstances (Minceirs Whiden, 2009). There are good reasons for this, with resonances for the wider literature on health promotion and on social inequalities. Firstly, this is seen as a classical form of 'victim-blaming' (McLeroy *et al.,* 1988). The person is responsible for their own poor health because, for instance, they continue to smoke, pursue a poor diet or drink to excess, a direct behaviourist interpretation (Levitt, 2000). To compound this paradigm is to say such individuals behave poorly because they are poor and if they would take steps to change this, such as obtaining somehow a viable income that was not state dependent, stay in education or otherwise conform to the wider social norm, then their problems would be resolved, (see Lynch *et al.,* 1997 for discussion of this issue).

It is well established in the health promotion literature also, as Blaxter and others have shown (Blaxter, 1987), that paradoxically the most disadvantaged are the last to agree with the proposition that they are disadvantaged, precisely because it renders them powerless if they agree that societal forces outside their control are patterning their situation. A reaction to this is to assert a cultural response, which is to say that the lack of recognition of the identity of Travellers explains the over-simplified view the general population holds towards Travellers, which is causing such corrosive negativity in their lives. If Travellers were afforded recognition, then, advocates would say, this leads onwards to a more empowered community. This position at its most assertive brooks no discussion at all about lifestyle.

Yet, all the recent evidence suggests the final common pathway to disease-specific outcomes is in fact mediated primarily through traditional risk factors. The INTERHEART global case control study of the causes of cardiovascular disease across 5 continents indicates little independent residual role for ethnicity, when all the conventional risk factors have been taken into account (Yusuf *et al.,* 2004; Rosengren *et al.,* 2004). It is the *patterns of distribution of these risk factors* that are culturally determined, and the role of certain psychosocial processes is highly culturally determined, both independent of, and mediated through, conventional risk factors (Marmot and Wilkinson, 2001; Davey-Smith *et al.,* 2000). Position on the social hierarchy and discretion to change are powerfully socially determined at community as well as individual level (Siegrist and Marmot, 2004).

What this means is that those most empowered are most likely to make life changes that promote their health. It is not that lifestyle is unimportant as a health determinant, but rather that it is the first thing to change if you are in control of your life and the last if you are not. *In this context knowledge about lifestyle is power, rather than an undermining of the dignity of one's social position.* Smoking presents an interesting paradox (Graham, 1987). As we already showed in Technical Report 1, prevalence rates are high and it

is a major risk factor for both respiratory and cardiovascular disease, both too high amongst Travellers according to Technical Report 2a. Yet it did not feature as a prominent issue in either the qualitative consultation or the service providers' study in Technical Reports 3a and 3b nor indeed in another recent Traveller consultation in Northern Ireland (McMahon, 2005). Clearly, as numerous investigators have pointed out, smoking and other lifestyle factors are not internalised as health determinants, but seen as a source of coping (Graham, 1987; Fitz-Simon *et al.,* 2007; Hodgins *et al.,* 2006). The Travellers in this study smoke more heavily than those in social classes 5 and 6, but not greatly so. They have dietary patterns based on strong and respected traditions, which have their origins in rational patterns of the past when butter and salt for instance were scarce commodities.

Health promotion skills programmes must therefore be sensitive and culturally specific, for instance addressing the traditional value placed on salt and butter in the diet, the strict hygiene codes in Traveller kitchens and the limits of cooking equipment in homes. There is increasing worry about the impact of drugs on the young in the community and patterns of binge drinking by those who do drink alcohol, all of which require collective as well as individualist policy strategies. Now that we have provided the evidence base, there is an opportunity to engage Traveller advocates and TCHWs on sound and effective health promotion policies.

To bring about these changes however, the big picture issues need to be addressed first. A recent robust systematic review of the health determinants policy literature suggests that some macro policy strategies, such as housing and accommodation are strongly evidence-based, others less so (Bambra *et al.,* 2010).

Racism, Discrimination and Disadvantage: Its Impact on Health and Wellbeing

In recent years the social capital literature has grown and it is now well established that aspects of immediate and wider community life can both promote and demote good health (Coleman 1988; Kawachi and Kennedy, 1997; Putnam, 1995; Kawachi *et al.,* 1999; Bourdieu, 1999; Berkman and Kawachi 2000; Kim *et al.,* 2006). All things being otherwise equal, a supportive community is a more positive place to be than an unsupportive community. Indicators associated with social capital include trust and participation, networks, personal support from significant others. The concept of Travellers as a community is integral to our understanding of their health status. Travellers self identify, share a culture and value systems, choose to socialise and congregate together, and value immediate and wider family networks. Bridging is an important concept in this literature, which entails 2-way communications with other groups, in this case between Travellers and the general community.

In more recent decades the traditional skills of barter and trade between Travellers and the general community have changed. A thing of the past is the nomadic tinsmith in rural life who performed a service in exchange for goods or food and who moved relatively freely in a society where most people were not particularly affluent anyway, but were largely self sufficient (Gmelch and Gmelch, 1976). The

whole basis of modern Irish society has shifted, it has become more polarised and sharply divided on class lines (Kelleher, 2007; Balanda and Wilde, 2001 and 2003), and traditional skills have been replaced by mass production of goods and services on which everyone now relies and must find monetary means to purchase. Some Travellers have adapted well with antique dealing, horse trading, sports and music participation but the mass of the community has not. The lack of a skill or trade and lack of earnings have created a dependence on state welfare and contributed to a sense of frustration and futility, according to our findings.

Travellers at all points of interface report higher levels of discrimination than expected and lower levels of trust in others and in health service providers. *Even if this was a collective misperception and had no basis in objective fact, such a perception is likely to lower a sense of efficacy and self esteem and this is damaging to mental health and wellbeing* (Kawachi and Kennedy, 1997; Marmot and Wilkinson, 2001; Marmot *et al.,* 2008). Regrettably, it is all too likely that there is a very real basis to this perceived discrimination. The general population often, with honourable exceptions, has little time for Travellers. Stereotypical portrayals of Travellers who are inordinately likely to commit crimes and perform hostile acts against settled people are routine. It is important also of course to put the converse case, as there is room for optimism also. Many health service providers and policy makers are committed to Traveller health, and supported all aspects of these studies, in planning, staff engagement and as participants in the surveys and consultation process. This goodwill extends into the general community and must be harnessed now into action.

We show clearly in this study in Technical Report 2c that Travellers have higher incarceration rates than the general population, but also that the vast majority of Travellers are not in prison. Similar issues arise for other indigenous minority groups. A campaign in New Zealand for instance highlights specifically the more positive message that most Máori are not in fact in prison (Department of Corrections, 2008). Bridging is the key concept and it is a 2-way process. The general population needs to learn more about Travellers, to distinguish the prejudiced stereotype of some from the more subtle position of others that Travellers are for instance more likely to fall foul of the law, but that there are many reasons determining why that may be so, and one of these is a failure of institutional systems to understand Traveller engagement at different levels of society.

Many Traveller advocates see racism and discrimination as the root cause of ill-health in the Traveller community and this extends to a need to see ethnicity acknowledged unequivocally to Travellers as a starting point in the building of trust. The scientific literature suggests that the resolution of this equation is necessarily complex (Paradies, 2006; Schulz *et al.,* 2006; Berkman and Glass, 2000; Krieger, 2003). As Krieger points out, the robust data are not always available. In the US, where the Black/White/Hispanic labelling has existed for decades, it can be difficult to distinguish the relative effects of ethnicity and poverty. As she states, a study that examines only ethnicity is likely to miss poverty as the determining feature, whereas one that considers only poverty in material terms, misses the subtlety of the racial or ethnic experience (Krieger, 2003). We took care to include both types of variables in this study for this precise reason.

Berkman and Glass (2000) propose models that address how factors such as race and culture influence health pathways both upstream and downstream at macro-policy level, at meso level through networks and communities and at group or individual level through daily health choices and decisions. Such a framework might usefully inform future policy in implementing the findings of this study.

Taking self-rated health as an indicator, often cited in the literature (Paradies, 2006) in the Traveller dataset, all the domains associated with disadvantage play a role in its determination, including neo-material and psychosocial processes but also existing illness and lifestyle risk factors (Whelan *et al.,* 2010). Service Providers generally rated these wider health determinants as important or very important influences on Traveller health also in Technical Report 3b. The precise causal pathways leading to social and health inequalities are vigorously contested in the literature. The neo-material school contends that the modern post industrial, particularly urban experience leads to a constellation of economic disadvantages for the poor (Lynch *et al.,* 2000). The psychosocial school maintains that the experience of relative inequality, the social position afforded by an individual is crucial to the sense of self, of coherence and empowerment to engage (Marmot and Wilkinson, 2003). The truth is likely to be forged from a position somewhere in between, but at its heart lies the reality that skills provide the core means of engagement and education is the key to that engagement.

Travellers are a significant indigenous minority grouping and need definitive representation in the National legislative process. Traveller advocacy groups have and will undoubtedly continue to function in capacity building and empowerment. The strong verbal and oral reasoning tradition should be promoted as a means of social discourse. In recent years, a wave of articulate spokespersons have started to find their voice, this should be the vanguard of a new norm. There is a distinct cross-sectoral challenge here that is difficult to address at local or regional level.

As we outline in Technical Report 3a and b, it is not just Traveller advocate groups who recognise both the cross-sector policy challenge and the need for high-level policy engagement, service providers share this concern also. Without political representation, Travellers continue to be atomised and voiceless when it comes to policy decision-making. The solution to circumvent this challenge in the past has been committees, quangos and agencies. However, Travellers are disenfranchised in a very practical sense by their relatively small numbers and scattered location. They can never hope, in the conventional political system to make an impact that would determine policy for their community, just by sheer dint of numbers. There is a need to review Traveller representation in all aspects of the political process, at local, regional and national level, including the Houses of the Oireachtais in the Republic of Ireland. There is a precedent for this in the International literature, which addresses various means of ensuring indigenous minorities can exercise a voice (Organization for Security and Co-operation in Europe, 1999). We suggest that what would serve well in the Republic of Ireland for instance is proportional representation in the Dáil, as a single virtual rather than geographic constituency. The Constitution sets out the conditions for having TD representation in article 16, section 2 (Bunreacht na hÉireann, 1937). Though as a community Travellers have sufficient numbers to justify the minimum requirement of a TD representative, they do not satisfy the constitutional requirement of a geographical three-seater constituency. There is in general increasing public interest in a constitutional review of

representation (Rogers, 2010). Provision does exist for boundary reviews on a purely geographical basis, last conducted in 2007 (Constituency Commission, 2007), which might be a starting point for discussion. TDs based on popular Traveller vote would serve to accustom engagement with the democratic process. This would foster a mutual learning process on the art of the possible, in political terms. Again a unique ethnic or cultural identifier (see further below) would serve as the register for voting and democratise the Traveller community in a way that has been impossible for decades.

What Characteristics of Accommodation and Housing Matter?

We examined the question of accommodation in great detail in this report and various aspects of this issue are explored fully in the census survey in Technical Report 1, the qualitative consultation with both Travellers and Service Providers and the quantitative survey of Service Providers, as well as in the literature we reviewed. We refer readers to these sections for further detail. We found that most Travellers are living in houses, but there is a wide range of accommodation experience and the most destitute of Travellers are living in very poor conditions indeed. During the recruitment phase of the survey we were concerned that these were the families hardest to access and yet most in need of support. The evidence from this study suggests that it is appropriate amenities, rather than type of accommodation that are important factors. We present data according to type of accommodation in Technical Report 1. The qualitative consultation also demonstrates the impact accommodation has on all aspects of the lives of Travellers. This extends from exposure to physical hazards in the poorer quality accommodation to impact on mental health and wellbeing of living in stressful situations. The significant predictors of self-rated health for instance were availability of a flush toilet, considering one's place of residence to be healthy and the discretion to go on the road at least twice a year (Whelan *et al.,* 2010). The majority of Travellers live in houses by choice and it is the adequacy and location of that accommodation that is important, not its type. The qualitative consultation again demonstrates that being housed in an area isolated from family and friends can be very difficult for Travellers. Service Providers recognised, both in interviews and as part of the survey, that accommodation adequacy is a key health determinant. Of those in a trailer, halting site or caravan, it is amenities that matter. In Northern Ireland, family sizes are smaller, younger and more mobile and pregnant women were more likely to report themselves in unsafe or insalubrious circumstances.

The controversy over Traveller accommodation policy is longstanding and well rehearsed and it is not for this report to add to the prolix discussion. What we can say is that the better accommodated the Traveller family, the better the health status. Rather than protracting the ideological debate, the recommendation should be to ensure existing policy is comprehensively implemented so that there are for instance adequate amenities on halting sites, with the basic principle that the children particularly in such situations have rights to a secure childhood and that need should be the primary driver of policy. Marmot's recent reviews for both WHO and UK government on health inequalities stress the importance of early life intervention, based on a strong international research evidence base (WHO, 2004; Marmot *et al.,* 2010), which includes adequate accommodation and our findings are congruent with that.

Access to Care: Psychosocial as well as Infrastructural Barriers

When the study was originally conceived many believed that there were major barriers to healthcare access that would emerge in the survey. In fact, as with many aspects of this study, the reality was more complex. For instance the overwhelming majority of Travellers, on both sides of the border, declared in the census that they had access, either to GP registration or to general medical services. Travellers mostly believed themselves to have the same kind of access as others to various levels of service, including Emergency Room (ER or A & E) services. Utilisation of GPs was somewhat higher than the general population and considerably so of ER services, but children's accident rates were not unduly higher than the general population surveys. There were even signs that some of the promotion of specialist services had been effective, as rates of reported women's health screening were in fact higher than the general GMS population, presumably facilitated by primary care projects.

However, engagement may be suboptimal. Travellers were much less likely than the general population to trust health professionals and to feel respected in such encounters, based on the census data. In the qualitative datasets many miserable accounts were proffered about treatment received and a general sense of not being understood and catered for by the system. The clinical training most health professionals receive can be counterproductive in this situation. Such professionals pride themselves on not showing any differentiation based on race, colour or creed, but if the approach is too neutral than it lacks empathy and a failure to understand the context or predicament of patients means they can't engage effectively. This is the basis of a worldwide ethnic minorities literature, which we reviewed, and it needs vigorous examination here.

The Service Provider survey provides evidence from those most frequently used to working with Travellers that they are less likely to engage with services in key indicators such as outpatient appointments. Travellers were less likely to avail of preventive care. Service providers also report that Travellers have difficulty with literacy and medication prescription issues, as Travellers themselves reported. The service providers report too that men were more likely to present late for care, and children early. The data suggests that there is insufficient training for key frontline providers on cultural aspects of Traveller healthcare. Notably, the Northern Ireland Service Providers were more supportive of an ethnic identifier than those in Republic of Ireland. This is interesting as such an identifier exists already in Northern Ireland.

Taken together, the three sources of information, from the census, the qualitative consultation and the Service Providers' survey suggest that there is considerable and feasible room for improvement in the quality of the healthcare encounter.

A key concept in this context is health literacy, an extension of the health promotion concept of people being empowered to achieve positive health outcomes (Nutbeam, 2000). This recognises that core skills are necessary to maintain health and negotiate health care systems. Those with challenges including general literacy will experience difficulty in making change and in achieving successful health outcomes. The case of cardiovascular disease is one in point. In fact there is no systematic

primary care detection system for cardiovascular risk factors in general and Travellers are no different from anyone else in this respect. However, relative to the risk they run they are not apparently having risk factors detected or treated. This phenomenon of unmet need was true in SLAN 1998 and in the Kilkenny Health Project, where a social gradient existed in detected CVD risk factors (Kelleher *et al.,* 2002; Shelley *et al.,* 1995) and more recently SLAN 2007 exhibited an inverse problem of under-ascertainment of smoking in more affluent GP patients (Brugha *et al.,* 2009). Given their high mortality, likely high incidence, and low appreciation of the risk factors in the community, it is appropriate to mount an opportunistic cardiovascular disease risk factor detection programme for Travellers.

The Case For and Against Unique Traveller Identifiers in Datasets

One issue that recurred in this study is the paucity of standard surveillance information. If all health service documentation contained a unique Traveller identifier then routine monitoring of trends would be facilitated and appropriate care provided. There is a general literature on unique identifier information for linking records and a more specific one on whether certain ethnic or minority groupings with distinct needs should have a means of identification in routine data systems. The registration process would have been much more straightforward if the equivalent of the census question on cultural and ethnic background, which includes a Traveller category, were available. It proved for instance impossible to collect really systematic information from prison databases despite cooperation of all parties. If general practice and hospital records held such information, in for instance GMS prescribing and HIPE information bases, then patterns of utilisation and treatment could be monitored. In the qualitative section, respondents were puzzled that transferable data were not available across healthcare systems. The principal investigator on this project recommended patient held records for Travellers to the original task force, but there has been no progress since. There is much to be said for having this information and methodology available and implementation of the identifier system piloted already is warranted. An ethnic and cultural background identifier, as used in 2006 census in Republic of Ireland for all health datasets is a key recommendation in the HSE National Intercultural Health Strategy (Health Service Executive, 2008).

What are the drawbacks to an ethnic or cultural identifier? First, there is the fear Travellers might have that they will somehow be discriminated against if they disclose a Traveller identity. This is a very real issue for Travellers, compounded by their fear of written information, which many for literacy reasons cannot read themselves to verify its accuracy. Service Providers at interview raised similar reservations in fact. The only way to combat this is to, on the one hand assure Travellers that the net result will be positive, and on the other to ensure that healthcare delivery staff are aware of the issues particular to Travellers. There also needs to be more 2-way dialogue between health professionals and Travellers on what code of practice is mutually acceptable in clinical settings, discussed further above in the section on access.

Who Needs to Do What to Put the Findings of this Study into Action?

There has been no shortage of policy production in the last 2 decades of relevance to Travellers. Nor is there a shortage of international literature and policies of direct relevance, what is required is translation of evidence into action. We do not seek to re-invent the wheel in this report, what we do is provide the evidence base that justifies expedition of the many existing recommendations made in recent policy documents. The Traveller community put its trust in this study and other stakeholders at all levels engaged with it to the credit of all parties; the results suggest an obligation on all stakeholders to translate the evidence of its findings into action. We have uncovered a life-or-death reality and it is as serious as that.

We highlight some key points below.

- **A strategic action plan should be set out, with a firm commitment to implementation, targets and timeframes.** We do not prescribe to the commissioners of this study how this is to be achieved but clearly it requires cross-sectoral engagement and a lead player or champion to deliver based on the findings of this report. We have shown that Travellers have distinct health needs and the challenge remains to close the gap between their health and that of the general population. This should be informed in part by the still valid recommendations of the Traveller Health Strategy (2002). At an operational level, initiatives and exemplars of good practice should be mainstreamed. Despite intensive investment in many areas of cross-sectoral intervention there has been little improvement in mortality and the gap has widened. This report is not intended as a critique of responsible agency activities, but the evidence base simply suggests a failure to improve the situation. For whatever reasons, Traveller public policy to date has not delivered and a clean sheet cross-sectoral strategy is required.

- **Adequacy of accommodation is essential to ensure health improvement for Travellers.** There should be no official halting site without basic amenities and a sufficient number of them to accommodate the travelling Travellers on the island. A charter negotiated between Travellers and the local authorities, overseen by the Minister for the Environment or its equivalent in both jurisdictions, could be drawn up and agreed on acceptable standards in relation to rubbish collection, keeping of animals and pets, and so on, to promote a neighbourly strategy for the future. We are simply restating what is already public policy in principle, be put into practice.

- The cornerstone remains education, whether in acquiring basic literacy, learning about one's culture and that of others, or acquiring life skills to get a job, negotiating the public service bureaucracy, achieving successful parenting or accessing health information. The debate on whether this should be mainstreamed or separate is longstanding and complex, but what seems clear is that delivery is not reaching the individual child to the benefit of that child in the conventional classroom setting. **The first-line objective is that every Traveller child should obtain the minimum equivalent of the Junior Certificate and that a similar percentage should go on through secondary school to professional or higher level education as the general population within 10 years.**

- **Strong attention should be given also to adult education,** for 3 reasons; firstly, the population is still very young, most people are under 30. Secondly, these are the parents and breadwinners of the immediate future. Thirdly education is the rate-limiting step to empowerment.

- A significant rate-limiting step is the establishment of mutual trust between Travellers and the rest of Irish society, on both sides of the border. **A national multi-level education campaign is required to help break down the stereotypes many people in the general population have about Travellers and produce a more rounded understanding.** The policy the media and other agencies have is contributing to this, implicitly or explicitly, in that many news stories are about a negative event and it is often mentioned after the fact that the incident is Traveller-related. The Traveller focus weeks and similar promotions organised by Traveller organisations regionally and nationally have led the way with novel approaches to communication but are not yet mainstreamed enough; this requires a concerted multi-level media strategy, centred on the evidence base this study provides. We recognise this will pose a planning challenge, but the very engagement in planning it will raise the awareness of the issues of relevance into the future.

- **As part of this campaign a National exhibition of Traveller crafts and traditions could be mounted, in the National Museum, as a mainstream event.** As we point out, capitalising on the positivities of Traveller culture provides important balance. The folklore archive at University College Dublin is for instance a rich repository of unseen material. Active art projects, and tourism development might indeed be a useful means of generating revenue, as Travellers, like other minorities have interesting traditions to share. Travellers do not lack positive role models, there are many well-known artists and sportspeople with a Traveller background, these should be engaged in supporting this process.

- What is an appropriate employment policy for Travellers? **The policy must be to treat the community like a small or medium enterprise and take a bottom-up strategy.** Traditional skills need to be re-created as their contemporary equivalent as well as more innovative strategies in line with the knowledge economy. Halfway or shelter schemes can even be counter-productive by perpetuating individuals in this limbo situation; the goal has to be a learned skill with employable potential. Cultural identity is key, not as a health determinant in itself but as a practical means of empowering and engagement.

- **The current undergraduate and graduate curricula for health and education professionals should explicitly include a module on Traveller health status and customs,** so that all are trained in the basics from first stages. There are some precedents for this, but it is not standard.

- **Hospitals with a significant Traveller catchment population should include a section on Travellers as part of routine staff inductions, general practices with a Traveller list should offer similar induction to staff and there should be a set of guidelines on how Traveller families are managed from frontline to discharge,** which are regularly reviewed. It is only when quality assured processes are put in place that a unique identifier system that Travellers can trust will be put in place.

There are 4 priority healthcare needs, based on the combined evidence from across the report, but most particularly the mortality data, which require a unique identifier to implement in practice.

- First, **all sectoral aspects of mother and child services merit top priority** to reduce infant mortality, support positive parenting outcomes and break the cycle of lifelong disadvantage that starts so early for Traveller families. Travellers value their children and Service Providers agree that children are their first priority. We produce data in all 3 technical reports that support this early life priority, from the mortality data, the census information on living conditions and from the utilisation of services sections, showing that Travellers would engage well with a concerted strategy focused on early life needs.

- Second, a gendered strategy needs to be adopted and **men's health issues need to be addressed specifically,** with an emphasis on empowerment and promotion of self-esteem for young Travellers of both sexes to improve mental health and wellbeing, but particularly drawing in the engagement of men. This requires a comprehensive cross-sectoral approach to facilitate work opportunity, break down the substance misuse problems and engage men in health service participation.

- Third, **there is a concerted need to address cause-specific issues for respiratory and cardiovascular disease.** This necessitates supportive and culturally appropriate strategies for all aspects of positive lifestyle as well as risk factor detection and management and the women peer leaders, particularly the TCHWs in the Primary Healthcare projects, are the agents for positive change here, since they have already been engaged in this process in various existing exemplars of good practice that require wider mainstreaming and adaptation.

- Fourth, many Travellers wanted services brought to them, but in reality, this kind of mobile service has been assayed in the past and failed. The utilisation of emergency services as a first line means that care will always be reactionary and hurried, rather than personalised, tailored and preventive, so an alternative focus is required. **Priority should be given to a new model of primary care delivery for Travellers dovetailed in the Republic of Ireland with the emergence of Primary, Continuing and Community care services, and in partnership with the Primary Healthcare for Travellers Project Networks.** By concentrating Traveller services into these new primary care units with a sufficient mass of staff with specialist training, a more proactive approach to services could be achieved. The mapping and scoping exercise gives us a clear geographical picture of where to start.

Our
Geels
All Ireland
Traveller
Health Study

DEPARTMENT
OF HEALTH & CHILDREN
AN ROINN SLÁINTE
AGUS LEANAÍ

Department of
Health, Social Services
and Public Safety

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

UCD
DUBLIN

DCU

All Ireland Traveller Health Study

Our Geels

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